

# Germ-line Genetic Enhancement and Human Rights

An Assessment of the Arguments Against Germ-line Genetic Enhancement  
Articulated by UNESCO's International Bioethics Committee and the  
Council of Europe

Candidate number: 9003

Submission deadline: 1 December 2018

Number of words: 19 537



## **Acknowledgements**

There are many people whom I would like to thank for all the help and support during the process of writing this thesis. First and foremost, I have to thank my supervisor, Jakob Elster, whose help and feedback have been invaluable. I would also like to thank my generous and kind flatmates, you have made this autumn endurable. Sivert, thank you for saving me the weekend I had to write and was not able to go to Nordmarkskapellet. Anna, thank you so much for proofreading my thesis. I also have to thank my family, who are always there for me. Finally, I would like to thank all my classmates and professors at the Norwegian Centre for Human Rights, it has been great to get to know you and to explore the field of human rights together these past two years.

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# 1 Introduction

## 1.1 Background and Research Question

”Precise ‘chemical surgery’ has been performed on human embryos to remove disease in a world first,” the BBC reported in September 2017.<sup>1</sup> Using a recently developed genome editing technique called ‘base editing’ researchers at Sun Yat-sen University in Guangzhou, China, were able to successfully remove beta-thalassemia, a genetic blood disorder, in lab-made human embryos.<sup>2</sup> Advancements in human genetics are about to revolutionize the medical field and offer “unprecedented tools against disease”.<sup>3</sup> These recent discoveries have “opened the door to a new paradigm”, according to Council of Europe rapporteur Petra de Sutter.<sup>4</sup> She emphasises that the improved knowledge in this field has the potential to be of great benefit to human beings, but she also stresses that there are “ethical and human rights risks” related to the application of this knowledge.<sup>5</sup>

Although research on germ-line editing in human embryos is still in an early stage, one of De Sutter’s concerns is that the new genetic technologies in the future will be applied to genetically enhance human embryos,<sup>6</sup> i.e. to alter the genetic make-up of an embryo for non-medical purposes.<sup>7</sup> This concern is shared by another leading organisation in the field of bioethics and human rights; the United Nations Educational, Scientific and Cultural Organization (UNESCO) and its International Bioethics Committee (IBC).<sup>8</sup> The Committee emphasises in its 2015 report that “[t]he goal of enhancing individuals and the human species by engineering the genes related to some characteristics and traits (...) impinges upon the principle of respect for human dignity.”<sup>9</sup> Hence, both the Council of Europe (CoE) and the IBC conclude that

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<sup>1</sup> Gallagher, “DNA surgery on embryos disease”

<sup>2</sup> Gallagher, “DNA surgery on embryos disease”

<sup>3</sup> UNESCO, *Report of the IBC on updating its reflections on the Human Genome and Human Rights*, executive summary

<sup>4</sup> Council of Europe, Parliamentary Assembly, *The Use of New Genetic Technologies in Human Beings*, report, Committee on Social Affairs, Health and Sustainable Development. Rapporteur: Ms Petra De Sutter, para. 1

<sup>5</sup> Council of Europe, Parliamentary Assembly, *The Use of New Genetic Technologies in Human Beings*, report, Committee on Social Affairs, Health and Sustainable Development. Rapporteur: Ms Petra De Sutter, para. 1

<sup>6</sup> Council of Europe, *The Use of New Genetic Technologies in Human Beings*, report, Committee on Social Affairs, Health and Sustainable Development. Rapporteur: Ms Petra De Sutter, para. 29

<sup>7</sup> The definition of enhancement will be further discussed in section 1.3

<sup>8</sup> UNESCO, *Report of the IBC on updating its reflections on the Human Genome and Human Rights*, executive summary

<sup>9</sup> UNESCO, *Report of the IBC on updating its reflections on the Human Genome and Human Rights*, para. 111

from a human rights perspective interventions on the human genome should be admitted for preventive, diagnostic or therapeutic reasons only, and never for enhancement purposes.<sup>10,11</sup>

Questions concerning the issue of germ-line genetic enhancement are not confined to human rights fora; they are also extensively discussed in the bioethical literature, in which ethical issues arising from advances in biology and medicine are explored from the perspective of several academic disciplines, in particular philosophy.<sup>12</sup> In the bioethical debate on germ-line enhancement there is a great variety of positions, and, contrary to the recommendations from the IBC and the Council of Europe, a significant number of commentators argue in favour of permitting germ-line enhancement when this is technologically possible and acceptably safe.<sup>13</sup>

As genetic interventions are no longer merely a literary scenario in science fiction novels, the debate on the ethics of enhancement is becoming increasingly relevant and important. The framework of universal human rights, “the only successfully globalised form of ethics”, according to the British Nuffield Council on Bioethics, is a natural foundation for the debate.<sup>14</sup> However, not all human rights defenders arrive at the same conclusion as the IBC and the Council of Europe regarding germ-line enhancement. Swedish philosopher Nick Bostrom argues for instance that, “enhancement technologies should be made widely available”, because “the wisest approach (...) is to embrace technological progress, while strongly defending human rights and individual choice”.<sup>15</sup> Hence, how does the IBC and the Council of Europe justify their position regarding the permissibility of genetic enhancement?

The aim of this thesis is to contribute to the enhancement discussion by assessing the arguments the IBC and the Council of Europe use to defend a prohibition on germ-line enhancement. This has, to my knowledge, not yet been done systematically. The arguments I will assess concern the autonomy of future individuals, the fear of eugenics, the importance of protecting the human genome, and, finally, the fear of an exacerbation of discrimination and

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<sup>10</sup> UNESCO, *Report of the IBC on updating its reflections on the Human Genome and Human Rights* (2015), para. 107

<sup>11</sup> Council of Europe, Parliamentary Assembly, *The use of new genetic technologies in human beings*, Recom. 2115 (2017)

<sup>12</sup> Kuhse et al., *Bioethics*, 1

<sup>13</sup> Sparrow, “A Not-So-New Eugenics”, 32

<sup>14</sup> Nuffield Council on Bioethics, *Genome Editing and Human Reproduction: Social and Ethical Issues*, p. 114, para. 4.34

<sup>15</sup> Bostrom, “In Defense of Posthuman Dignity”, 208

stigmatisation. The thesis will also be a response to the Council of Europe's call for a public debate on the possible ethical consequences of introducing new genetic technologies.

The research question is therefore:

*What are the strengths and weaknesses of the arguments against germ-line genetic enhancement articulated by the International Bioethics Committee and the Council of Europe?*

## **1.2 Methodology**

The thesis belongs to the field of ethics. In order to give an answer to the research question, I will discuss the strengths and weaknesses of the arguments against germ-line enhancement articulated by the IBC and the Council of Europe in the light of the bioethical literature. Below, I will explain how I have worked in order to answer the research question.

First I examined documents and instruments on bioethics produced by the IBC/UNESCO and the Council of Europe in order to find the arguments they use to justify their position on germ-line enhancement. These organisations are the two leading international bodies in the field of bioethics and human rights. I found five main arguments against permitting enhancement in these documents. They concerned the autonomy of future individuals, the fear of eugenics, the importance of protecting the human genome, and the fear of an exacerbation of discrimination and stigmatisation.

Secondly, I studied the bioethical literature in order to find works that discuss issues related to the arguments presented by the IBC and the Council of Europe. It has not been possible to examine the entire bioethical literature. Therefore, as a starting point, I used the 2018 report on genome editing and human reproduction produced by the British Nuffield Council on Bioethics.<sup>16</sup> This report provides a comprehensive presentation of the debate on germ-line interventions, as well as references to relevant literature. I also used the book *The Ethics of Human Enhancement: Understanding the Debate* as a starting-point, as the first chapter of the book outlines the central discussions of the enhancement debate, as well as many of its principal commentators.<sup>17</sup> Hence, these two works lead me to many relevant sources (these will be mentioned in chapter 2). As my objective has been to discuss the strengths and weaknesses of the arguments produced by the IBC and the Council of Europe, I have attempted to find the

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<sup>16</sup> Nuffield Council on Bioethics, *Genome Editing and Human Reproduction: Social and Ethical Issues*

<sup>17</sup> Clarke et al., *The Ethics of Human Enhancement*

most convincing arguments and counterarguments on both sides. However, it is important to note that such an assessment is subjective.

Thirdly, in order to assess the arguments I found in the documents from the IBC and the Council of Europe, I first needed to interpret them. Most of the arguments are only described in a few sentences, or less, and it is not always clear what the IBC or the Council of Europe means.

After having interpreted the arguments, I discussed them in the light of the arguments and counterarguments I had found in the bioethical literature, which revealed some of the strengths and weaknesses of the arguments. However, I was not able to find much literature that dealt with the IBC's argument concerning the human genome. Therefore the discussion in the section on the human genome (subchapter 4.4) will draw less on the bioethical literature.

### **1.3 Structure of Thesis**

The structure of the thesis will be as follows: The next section of this chapter will give a definition of 'enhancement' and a brief update on the state of developments in the field of genetic engineering. The final section of this chapter will explain the limitations of this thesis.

Chapter 2 will provide a brief literature review. The chapter will first describe the existing literature on bioethics and human rights that I have found, secondly it will elaborate on the enhancement debate in the bioethical literature and, finally, it will also briefly present the 2018 Nuffield Council report.

The aim of chapter 3 is to examine the bioethical instruments of UNESCO and the Council of Europe in order to identify the arguments they use to defend a prohibition on genetic enhancement.

The main discussion of the thesis is found in chapter 4. This chapter will draw on the bioethical literature in order to discuss the strengths and weaknesses of the arguments found in chapter 3. Chapter 4 is divided into four parts:

- Eugenics
- Discrimination and stigmatisation
- Autonomy of future persons
- The human genome and human dignity

Finally, chapter 5 will summarize the findings of the thesis and draw a conclusion.

## 1.4 Enhancement and Genome Editing

This section will first provide a definition of ‘enhancement’, and, secondly, it will give a brief introduction to the state of the developments regarding genome editing.

### 1.4.1 Enhancement Defined

Alberto Giubilini et al. define ‘human enhancement’ as “any kind of genetic, biomedical, or pharmaceutical intervention aimed at improving human dispositions, capacities and well-being, even when there is no pathology to be treated”.<sup>18</sup> Therefore, in the bioethical literature, enhancement is often contrasted with therapeutic interventions that aim to cure or prevent a disease.<sup>19</sup> There is, however, an on-going debate on whether it is possible to make a firm distinction between therapy on the one hand, and enhancement on the other.<sup>20,21</sup>

Examples of human enhancement include embryo selection (which can be done during in vitro fertilization (IVF) procedures), taking enhancing drugs and “inserting and deleting gene sequences”, Giubilini et al. explain.<sup>22</sup> In this thesis I will focus on genetic enhancements only, i.e. genome editing for enhancement purposes. Such enhancements can be either somatic or germ-line genetic enhancements. The aim of the former is to alter somatic cells, which means that the modification will not be inherited by the person’s descendants.<sup>23</sup> The latter type of enhancement, on the other hand, aims to alter germ cells or early embryo, which means that the modifications may be heritable.<sup>24</sup> This thesis will, as already stated, focus on germ-line genetic enhancement. If not stated otherwise, I always refer to germ-line genetic enhancement when I use the expression ‘enhancement’.

### 1.4.2 State of the Developments

Research on genome editing in human embryos is still in an early stage.<sup>25</sup> As mentioned in the first section of the thesis, Chinese scientists were in 2017 able to genetically edit human em-

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<sup>18</sup> Giubilini et al. “Challenging Human Enhancement”, 1

<sup>19</sup> Resnik, “The Moral Significance of the Therapy-Enhancement Distinction in Human Genetics”, 189

<sup>20</sup> National Academies of Sciences et al., *Human Genome Editing: Science, Ethics, and Governance*, 145-148

<sup>21</sup> One example could be an intervention aimed at improving the human immune system. Such an intervention would be related to health, but if it were not undertaken in order to restore or sustain health, one could also argue that it could qualify as an enhancement, because the improvement went beyond normal health.

<sup>22</sup> Giubilini et al. “Challenging Human Enhancement”, 1

<sup>23</sup> Resnik, “The Moral Significance of the Therapy-Enhancement Distinction in Human Genetics”, 189

<sup>24</sup> UNESCO, *Report of the IBC on Pre-implantation Genetic Diagnosis and Germ-line Intervention*, para. 79.

<sup>25</sup> Nuffield Council on Bioethics, *Genome editing and human reproduction: social and ethical issues*, para. 2.12

bryos and successfully remove a genetic disease.<sup>26</sup> These embryos were not, however, implanted, i.e. no pregnancy was established with the embryos.<sup>27</sup>

In their report on genome editing and human reproduction published in July 2018, the Nuffield Council on Bioethics notes that it is possible “that the first step into clinical use may never happen for heritable genome editing interventions.”<sup>28</sup> However, the genome editing technique CRISPR/Cas9 has been a game changer since its emergence in 2012.<sup>29</sup> The technique enables “precisely targeted alterations to DNA sequences in living cells”, the Nuffield Council report explains.<sup>30</sup> As a result of the invention of CRISPR, it is possible to envisage that we one day are able to “deliberately [intervene] in the human genome for the purposes of selecting traits of future children”.<sup>31</sup>

These prospects have made the discussion regarding the ethics of germ-line intervention one of the most important debates on ethics and technology today. Key questions in the debate are whether germ-line interventions should be permitted if the procedure is considered to be acceptably safe, and, furthermore, if they are permitted, what kinds of germ-line interventions should be admitted. Should only therapeutic interventions be permitted, or should also interventions for enhancement purposes be permitted?

Permitting germ-line interventions would be contrary to the European Convention on Human Rights and Biomedicine, which contains a prohibition on all heritable genome editing interventions.<sup>32</sup> The Convention has been ratified by 29 European states.<sup>33</sup> However, Article 32 provides that the Convention can be amended in the light of scientific developments.<sup>34</sup> The Convention will be further discussed in chapter 3.

## 1.5 Limitations

In this section I will explain three important limitations of the thesis.

First, as explained in the section above, there are several ways to enhance a person’s capacities. This thesis will only discuss germ-line genetic enhancement, i.e. prenatal genetic

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<sup>26</sup> Gallagher, “DNA surgery on embryos disease” (2017)

<sup>27</sup> Gallagher, “DNA surgery on embryos disease”

<sup>28</sup> Nuffield Council on Bioethics, *Genome editing and human reproduction: social and ethical issues*, para. 2.2

<sup>29</sup> Nuffield Council on Bioethics, *Genome editing and human reproduction: social and ethical issues*, Foreword

<sup>30</sup> Nuffield Council on Bioethics, *Genome editing and human reproduction: social and ethical issues*, Foreword

<sup>31</sup> Nuffield Council on Bioethics, *Genome editing and human reproduction: social and ethical issues*, Foreword

<sup>32</sup> Convention on Human Rights and Biomedicine (1997)

<sup>33</sup> Committee on Bioethics, *Chart of signatures and ratifications of*

<sup>34</sup> Convention on Human Rights and Biomedicine (1997), art. 32

interventions for enhancement purposes. As I understand the arguments of the IBC and the Council of Europe, their concerns are primarily related to this kind of enhancement, therefore this will also be the focus of the thesis.

Secondly, many commentators argue that the line between interventions for enhancement purposes on the one hand, and interventions for health purposes on the other, is blurred, and that it is hard to defend a strict distinction between the two. This discussion is very important, however, due to the space limitation, I will not be able to elaborate on the discussion.

Thirdly, in discussions on reproductive genetic technologies it is often referred to the so-called non-identity problem. As this thesis will focus on germ-line interventions and not embryo selection, the non-identity problem is not directly relevant and will not be discussed.

## 2 Literature Review

The aim of this chapter is to provide a brief literature review. I will first describe the literature I have found where bioethics is discussed in relation to human rights. Secondly, I will elaborate on the different positions in the enhancement debate in the bioethical literature and, finally, I will briefly present the 2018 Nuffield Council report.

### 2.1 Literature on Bioethics and Human Rights

I have not been able to find very many academic works that discuss bioethics in relation to human rights. Hence, I hope this thesis can contribute to the debate by discussing enhancement from the human rights perspective of UNESCO/IBC and the Council of Europe. I have, however, found two books that contribute to the discussion on bioethics and human rights. These are: *Children's Bioethics* by Maya Sabatello<sup>35</sup> and *Biomedicine, the Family and Human Rights* by Marie-Therese Meulders-Klein et al.<sup>36</sup> Below, I will briefly describe the topics of these books. I will begin with the book by Sabatello.

*Children's bioethics: The International Biopolitical Discourse on Harmful Traditional Practices and the Right of the Child to Cultural Identity* was published in 2009. The author uses the international human right framework, especially the UN Convention on the Rights of the Child, to discuss biomedical practices from a child-centred approach. The last chapter of the book deals with prenatal genetic interventions and the child's right to identity. Sabatello argues that genetic interventions performed in order to cure a disabling condition could infringe the child's right to preserve his or her identity.

*Biomedicine, the Family and Human Rights* contains the lectures from a conference on biomedicine and human rights that took place in Oxford in 1999. It was organised by the International Society of Family Law. The objective of the conference was to "examine the impact of advances in genetics and assisted reproductive technologies on family law, human rights and the rights of the child".<sup>37</sup> The first part of the book presents "the general framework", including the European Convention on Bioethics and Human Rights. The second part of the book consists of national reports from various Western countries discussing national legislation on reproductive technologies, and the impact of human rights conventions on this legislation.

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<sup>35</sup> Sabatello, *Children's Bioethics*

<sup>36</sup> Meulders-Klein et al., *Biomedicine, the Family and Human Rights*

<sup>37</sup> Meulders-Klein et al., *Biomedicine, the Family and Human Rights*, preface

None of the books deals directly with genetic enhancement. Sabatello focuses on therapeutic interventions, while the themes of *Biomedicine, the Family and Human Rights* are primarily related to *in vitro* fertilization and cloning. Therefore, the books are not very central to the discussion of this thesis. In the next section I will elaborate on the enhancement debate in the bioethical literature and present the authors whose work I draw upon in this thesis.

## **2.2 The Enhancement Debate in the Bioethical Literature**

There is, as already mentioned, a great variety of positions in the bioethical literature regarding the ethics of genetic enhancement. The aim of this section is to give a brief overview of the main positions. In order to do so, I will organise the positions into three main categories: proponents of germ-line genetic enhancement, moderates and bioconservatives.<sup>38</sup> However, also within the categories there are disagreements between the commentators, and the boundaries between the categories are blurred. I will first turn to the proponents of enhancement, secondly I will describe to the moderate position, and finally, I will elaborate on the bioconservative position.

### **2.2.1 Proponents of Germ-line Genetic Enhancement**

Authors who belong to the first category find germ-line genetic enhancement to be morally permissible and believe enhancement technologies have great potential in terms of improving people's lives. They disagree with those who claim that enhancement is "beyond the proper ends of medicine",<sup>39</sup> and argue that making a firm distinction between therapeutic interventions on the one hand and enhancement on the other, is morally insignificant as they both share the same objective,<sup>40</sup> namely to increase "the chances of leading a good life".<sup>41</sup> Proponents of enhancement furthermore acknowledge that there are potential risks related to germ-line enhancement, but believe that proper regulation and other measures will contribute to solving the problems that may arise.<sup>42</sup> Consequently, they believe that the potential benefits of enhancement will outweigh the potential risks. In the following sections I will first concretise

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<sup>38</sup> These categories are inspired by the ones used in Giubilini and Sanyal's chapter in Clarke et al. *The Ethics of Human Enhancement*

<sup>39</sup> Giubilini et al. "Challenging Human Enhancement", 1

<sup>40</sup> Giubilini et al. "Challenging Human Enhancement", 2

<sup>41</sup> Savulescu et al. "Well-being and enhancement", 7

<sup>42</sup> Giubilini et al. "Challenging Human Enhancement", 2

what some of these benefits might be, and secondly, I will address a couple of issues that proponents of enhancement disagree on.

### 2.2.1.1 *Benefits of Enhancement*

Nick Bostrom<sup>43</sup> believes that enhancement technologies will “offer enormous potential for deeply valuable and humanly beneficial uses”, such as giving human beings increased health-spans and greater intellectual and physical capacities.<sup>44</sup> These technologies could give parents the opportunity to give their children the best life they can have, and, as Dov Fox asks: “What mother or father does not want to give his or her child the best chance at leading a happy and successful life?”<sup>45</sup> (This issue will be further discussed in chapter 4.3.2)

Moreover, Julian Savulescu argues that genetic enhancement can contribute to a more fair and equal society: “Nature allots capabilities and disabilities unequally, with no mind to fairness”, however, Savulescu argues, “by manipulating the biological determinants of the good life, we could ensure that people have the capacity to have a good life”.<sup>46</sup> He explains that intelligence is one such biological determinant that could be manipulated in order to give people with a low IQ a “decent chance of a decent life”.<sup>47</sup>

### 2.2.1.2 *Internal Disagreements*

Among the proponents of enhancement, there is also disagreement over a number of issues, including, for instance, who should be allowed to make decisions about germ-line enhancement, what kinds of enhancements that should be permitted, and whether some specific enhancements should be encouraged or even morally obligatory. Regarding the first questions, some proponents of enhancement argue that genetic enhancement decisions should be made by the parents of the child alone,<sup>48</sup> whereas others, such as Dov Fox, also argue that the government has a responsibility to *mandate* certain “safe, effective, and functionally integrated genetic practices”.<sup>49</sup> (This issue will be elaborated on in chapter 4.1.3). Concerning the second

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<sup>43</sup> Bostrom belongs to the so-called transhumanist movement. Transhumanists believe human nature should be improved “through the use of applied science and other rational methods”. (Bostrom “In Defense of Posthuman dignity, 208)

<sup>44</sup> Bostrom, “In Defense of Posthuman Dignity”, 208

<sup>45</sup> Fox, “Silver Spoons and Golden Genes”, 576

<sup>46</sup> Savulescu, “Justice, Fairness and Enhancement”

<sup>47</sup> Savulescu, “Justice, Fairness and Enhancement”

<sup>48</sup> Fox, “The Illiberality of Liberal Eugenics”, 3

<sup>49</sup> Fox, “The Illiberality of Liberal Eugenics”, 1

question about what sorts of enhancement that should be permitted some argue that it should be entirely up to the parents to decide what enhancements they want to use, so long as they do not choose an enhancement that will harm the child.<sup>50</sup> There are also some commentators who argue that certain enhancements should be morally obligatory. Newson and Williamson argue for instance that, “optimisation of intelligence is morally demanded in Western societies, as long as the process to achieve this do not impose social harms”.<sup>51</sup>

In chapter 4 I will also draw on the work of James Hughes,<sup>52</sup> David Resnik,<sup>53</sup> Frances Kamm<sup>54</sup> and Allen Buchanan et al.,<sup>55</sup> who also belong among the proponents of enhancement.

### 2.2.2 The Moderate Position

The moderate position include those authors who emphasise the potential risks and slippery slope concerns related to germ-line enhancement, but who do not believe that such interventions are inherently unethical. Erik Parens, Robert Sparrow, Jürgen Habermas and John Robertson, whose work I will refer to in the discussions in Chapter 4, are authors I will place within this category. Below, I will briefly describe a few of their concerns.

In his article “The Goodness of Fragility”, Parens argues that since we do not know what consequences genetic enhancement may have for human beings and society, we should “proceed with extreme caution”.<sup>56</sup> His concern is that enhancement technologies might affect society’s relationships of care, as well as its diversity, as will be elaborated on in chapter 4.2.<sup>57</sup>

Sparrow’s concern is that enhancement technologies will contribute to reviving coercive eugenic practices, i.e. coercive practices aimed at improving the human gene pool.<sup>58</sup> Although proponents of enhancement argue that allowing parents to voluntarily improve the genes of their children is a ‘liberal’ form of eugenics very different from the racial hygiene practices of the Nazis, Sparrow nevertheless fear that if enhancement techniques become

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<sup>50</sup> Hughes, “Embracing Change With all Four Arms”

<sup>51</sup> Newson et al., “Should We Undertake Genetic Research on Intelligence?”, 205

<sup>52</sup> Hughes, “Embracing Change With all Four Arms”

<sup>53</sup> Resnik, “The Moral Significance of the Therapy-Enhancement Distinction in Human Genetics”,

<sup>54</sup> Kamm, “Is There a Problem With Enhancement?”

<sup>55</sup> Buchanan et al. *From Chance to Choice*

<sup>56</sup> Parens, “The Goodness of Fragility”, 141

<sup>57</sup> Parens, “The Goodness of Fragility”, 141

<sup>58</sup> Sparrow, “A Not-So-New Eugenics”

available, parents will not experience that they have much choice but to use them. (This issue will be further explored in chapter 4.1.)

Finally, Habermas fears that enhancement practices might change how human beings view themselves.<sup>59</sup> Knowing that one's characteristics have been determined by another person can influence one's understanding of oneself as an autonomous and equal member of society. However, this is only true for specific enhancements, Habermas argues, more general enhancements such as increasing the child's lifespan, can be morally justified because the future child is likely to consent to such an enhancement.<sup>60</sup> (Chapter 4.3 will elaborate on this issue.)

### 2.2.3 The Bioconservative Position

The last position I will briefly describe is the bioconservative position. Bioconservatives believe that germ-line enhancement is inherently wrong and, accordingly, should be prohibited.<sup>61</sup> They believe that the goal of biomedicine should be to treat and prevent diseases, not to enhance the capacities of human beings beyond normal health.<sup>62</sup> Bioconservatives often invoke terms such as 'human dignity', 'sanctity' and 'playing God' in order to explain why enhancement is morally wrong.<sup>63</sup> They believe that human nature has a special status, and should not be tampered with. Hence, to alter human nature in such a fundamental way as genetic enhancement technologies would, cannot be justified. Many bioconservatives also believe that human dignity is closely linked to human nature; all human beings have equal dignity because they share the same human nature.<sup>64</sup> Thus, if enhancement technologies change 'human nature' this might jeopardise "the idea of a natural equality among human beings".<sup>65</sup> (This issue will be further explored in chapter 4.4)

In his famous book "The Case Against Perfection", Michael Sandel argues that the main problem with enhancement is that it will result in what he calls a "drive to mastery".<sup>66</sup> He explains that enhancement technologies represent "a promethean aspiration" to remake

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<sup>59</sup> Habermas, *The Future of Human Nature*

<sup>60</sup> Habermas *The Future of Human Nature*, 51-52

<sup>61</sup> Giubilini et al. "Challenging Human Enhancement", 2

<sup>62</sup> Giubilini et al. "Challenging Human Enhancement", 2

<sup>63</sup> Giubilini et al. "Challenging Human Enhancement", 2

<sup>64</sup> Giubilini et al. "Challenging Human Enhancement", 11

<sup>65</sup> Giubilini et al. "Challenging Human Enhancement", 11

<sup>66</sup> Sandel, *The Case Against Perfection*, 27

human nature “to serve our purposes and satisfy our desires”,<sup>67</sup> and that this will destroy our “openness to the unbidden”, and consequently jeopardise the sense of solidarity and humility among humans.<sup>68</sup> (I will elaborate on Sandel’s argument in chapter 4.2)

What is furthermore worth noting, is Sandel’s criticism of the approach to bioethics taken “[i]n liberal societies”, as opposed to his own approach.<sup>69</sup> He explains that they “reach first for the language of autonomy, fairness and individual rights”, but that this language does not “equip us to address the hardest questions posed by cloning, designer children and genetic engineering.”<sup>70</sup> He argues that these questions, such as the question concerning the moral status of nature, need to be confronted.<sup>71</sup>

In addition to Sandel, I will also draw on the work of the bioconservative authors Leon Kass,<sup>72</sup> George Annas<sup>73</sup> and Francis Fukuyama<sup>74</sup> in the discussions in chapter 4. In the next section I will briefly present the 2018 Nuffield Council report.

### **2.3 The Nuffield Council Report on Genome Editing and Human Reproduction**

The British Nuffield Council on Bioethics is an independent organisation whose work consists in examining ethical issues arising in the field of biomedicine.<sup>75</sup> One of their previous reports is cited in the 2015 report of the UNESCO’s International Bioethics Committee.<sup>76</sup>

In July 2018 the Nuffield Council published a 183 pages long report entitled “Genome Editing and Human Reproduction: Social and Ethical Issues”.<sup>77</sup> The report describes both the latest technological developments, and discusses the ethical issues this development prompts. The report also elaborates on the contents of the European Convention on Human Rights and Biomedicine<sup>78</sup> and on the UNESCO Declaration on the Human Genome and Human Rights,<sup>79</sup>

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<sup>67</sup> Sandel, *The Case Against Perfection*, 27

<sup>68</sup> Sandel, *The Case Against Perfection*, 45, 86

<sup>69</sup> Sandel, *The Case Against Perfection*, 9

<sup>70</sup> Sandel, *The Case Against Perfection*, 9

<sup>71</sup> Sandel, *The Case Against Perfection*, 9

<sup>72</sup> The President’s Council on Bioethics, *Human Cloning and Human Dignity: An Ethical Inquiry*.

<sup>73</sup> Annas et al., *Protecting the Endangered Human*

<sup>74</sup> Fukuyama, *Our Posthuman Future*

<sup>75</sup> Nuffield Council on Bioethics, *About, exploring ethical issues in biology and medicine*

<sup>76</sup> UNESCO, *Report of the IBC on updating its reflection on the human genome and human rights*, para. 118.

<sup>77</sup> Nuffield Council on Bioethics, *Genome Editing and Human Reproduction: Social and Ethical Issues* (2018)

<sup>78</sup> Convention on Human Rights and Biomedicine (1997)

<sup>79</sup> *Universal Declaration on the Human Genome and Human Rights* (1997)

and it discusses ethical issues using “the language and concepts of human rights”.<sup>80</sup> Thus, the report has been a very useful source for this thesis.

The report concludes, contrary to the European Convention on Human Rights and Biomedicine, that “the use of heritable genome editing interventions to influence the characteristics of future generations could be ethically acceptable in some circumstances”.<sup>81</sup> The moral acceptability of such interventions depends on whether they are consistent with the key principles of the report: “the welfare of the future person” and “social justice, and solidarity”.<sup>82</sup> If they are, the interventions are permissible. The report does not explicitly distinguish between therapy and enhancement, consequently, it is reasonable to believe that both kinds of intervention could potentially be consistent with the principles.

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<sup>80</sup> Nuffield Council on Bioethics, *Genome Editing and Human Reproduction: Social and Ethical Issues*, para. 3.2

<sup>81</sup> Nuffield Council on Bioethics, *Summary Report, Genome Editing and Human Reproduction: social and ethical issues*

<sup>82</sup> Nuffield Council on Bioethics, *Genome Editing and Human Reproduction: Social and Ethical Issues, Summary*

### **3 International Bioethics and Human Rights Instruments**

UNESCO and the Council of Europe are the two leading intergovernmental organisations in the field of bioethics and human rights. UNESCO has adopted three declarations on bioethics,<sup>83</sup> while the Council of Europe initiated the European Convention on Biomedicine and Human Rights.<sup>84</sup> The Declarations and the Convention aim to protect human rights, and promote progress in the field of biomedicine that is beneficial to both present and future generations. This chapter will elaborate on the legal instruments and recommendations related to genetic enhancement that have been produced by UNESCO and the Council of Europe, in order to find the arguments the bodies use to defend their position on enhancement. These arguments will be assessed in the next chapter.

#### **3.1 United Nations Educational, Scientific and Cultural Organization (UNESCO)**

UNESCO is a UN specialised agency whose purpose is to promote international cooperation in the fields of education, science and culture.<sup>85</sup> It is therefore also the UN body dealing with bioethical questions, working on “identifying universal principles based on shared ethical values to guide scientific and technological development”.<sup>86</sup> UNESCO has so far adopted three declarations on bioethics,<sup>87</sup> of which the first declaration, on the human genome and human rights, was also endorsed by the UN General Assembly in 1998.<sup>88</sup>

None of the Declarations directly mention the issue of genetic enhancement. Germ-line interventions in general are only mentioned in Article 24 of the first Declaration where it is given as an example of a practice that “could be contrary to human dignity”.<sup>89</sup> The International Bioethics Committee (IBC), the body responsible for following up the Declarations, does, on the other hand, discuss the issue of genetic enhancement from a human rights per-

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<sup>83</sup> *Universal Declaration on the Human Genome and Human Rights (1997), International Declaration on Human Genetic Data (2003), Universal Declaration on Bioethics and Human Rights (2005)*

<sup>84</sup> *Convention on Biomedicine and Human Rights (1997)*

<sup>85</sup> UNESCO, *UNESCO in brief*

<sup>86</sup> *Universal Declaration on Bioethics and Human Rights (2005)* UNESCO, preamble

<sup>87</sup> *Universal Declaration on the Human Genome and Human Rights (1997), International Declaration on Human Genetic Data (2003), Universal Declaration on Bioethics and Human Rights (2005)*

<sup>88</sup> UNESCO, *Report of the IBC on updating its reflections on the Human Genome and Human Rights*

<sup>89</sup> *Universal Declaration on the Human Genome and Human Rights (1997)* UNESCO, Art. 24

spective in several of their reports.<sup>90</sup> The next section will elaborate on their observations and conclusions in two of these reports.

### 3.1.1 International Bioethics Committee

In 2003 the IBC published a report on pre-implantation genetic diagnosis and germ-line intervention examining, amongst other things, the ethics of genetic enhancement.<sup>91</sup> The conclusion of the report is that genetic interventions should only be admitted for health purposes.<sup>92</sup> The same conclusion is found in the Committee's 2015 report.<sup>93</sup> Below I will present the arguments the Committee uses, starting with those given in the 2003 report.

In their first report, the IBC gives three main arguments against the use of germ-line genetic enhancement: First, the Committee claims that predetermining the characteristics of future generations would be wrong:<sup>94</sup>

*The notion of justice between generations (...) demands respect for the living conditions of future individuals who should be free to develop their potentialities without being biologically conditioned by the particular conceptions of 'good' and 'bad' human traits that were dominant at the time they were conceived*<sup>95</sup>

Secondly, the Committee is worried that genetic enhancement could “profoundly affect our self-perception as ‘persons’ – that is as autonomous beings”, with the consequence that we would “consider ourselves to be mere ‘things’ or biological artefacts.”<sup>96</sup> The third objection the IBC makes is that enhancement might “reinforce stigmatisation and discrimination of those who do not fall into the accepted standards of genetically desirable traits.”<sup>97</sup>

The Committee's 2015 report is entitled *Report of the IBC on updating its reflections on the Human Genome and Human Rights*. In the report the Committee elaborates on “five ethical principles and societal challenges”, which are: respect for autonomy and privacy; jus-

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<sup>90</sup> *Universal Declaration on the Human Genome and Human Rights* (1997) UNESCO, Art. 24

<sup>91</sup> UNESCO, *Report of the IBC on Pre-implantation Genetic Diagnosis and Germ-line Intervention* (2003)

<sup>92</sup> UNESCO, *Report of the IBC on Pre-implantation Genetic Diagnosis and Germ-line Intervention* (2003)

<sup>93</sup> UNESCO, *Report of the IBC on updating its reflections on the Human Genome and Human Rights* (2015)

<sup>94</sup> UNESCO *Report of the IBC on Pre-implantation Genetic Diagnosis and Germ-line Intervention* (2003), para. 97.

<sup>95</sup> UNESCO *Report of the IBC on Pre-implantation Genetic Diagnosis and Germ-line Intervention* (2003), para. 97.

<sup>96</sup> UNESCO *Report of the IBC on Pre-implantation Genetic Diagnosis and Germ-line Intervention* (2003), para. 98.

<sup>97</sup> UNESCO *Report of the IBC on Pre-implantation Genetic Diagnosis and Germ-line Intervention* (2003), para. 99.

tice and solidarity; understanding of illness and health; the cultural, social and economic context of science, and the responsibility towards future generations.<sup>98</sup>

The Committee discusses non-medical interventions primarily in two paragraphs of the report.<sup>99</sup> Here the Committee argues that enhancement “introduces the risk of new forms of stigmatisation and discrimination of those who cannot afford such enhancement or simply do not want to resort to it.”<sup>100</sup> The IBC is furthermore concerned that eugenics might be renewed if non-medical interventions on the human genome is permitted.<sup>101</sup> Finally, they also argue that altering the human genome could “jeopardise the inherent and therefore equal dignity of all human beings”.<sup>102</sup>

In sum, the IBC’s arguments and concerns are related to the fear of eugenics, the importance of the human genome, the commitment to the autonomy and freedom of future individuals, and, finally, to the fear of an exacerbation of discrimination and stigmatisation.

### 3.2 Council of Europe

The Council of Europe was founded in 1949.<sup>103</sup> The objectives of the Council are to promote human rights, democracy and the rule of law in Europe, particularly in its 47 member states.<sup>104</sup> As a result of developments in the biomedical field the Parliamentary Assembly of the Council adopted a recommendation “on the preparation of a convention on bioethics” in 1991.<sup>105</sup> This resulted in the Convention on Human Rights and Biomedicine<sup>106</sup> (the ‘Oviedo Convention’), which was opened for signature on 4 April 1997.<sup>107</sup> The Convention has been

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<sup>98</sup> UNESCO *Report of the IBC on updating its reflection on the human genome and human rights* (2015), executive summary

<sup>99</sup> UNESCO *Report of the IBC on updating its reflection on the human genome and human rights* (2015) para. 107. and para. 111

<sup>100</sup> UNESCO *Report of the IBC on updating its reflection on the human genome and human rights* (2015) para. 111.

<sup>101</sup> UNESCO *Report of the IBC on updating its reflection on the human genome and human rights* (2015), para. 107.

<sup>102</sup> UNESCO *Report of the IBC on updating its reflection on the human genome and human rights* (2015), para. 107.

<sup>103</sup> Meulders-Klein et. al., *Biomedicine, the Family and Human Rights*, 3

<sup>104</sup> Council of Europe, *Who we are*

<sup>105</sup> Convention on Human Rights and Biomedicine (1997), preamble

<sup>106</sup> Convention for the Protection of Human rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine

<sup>107</sup> Council of Europe, *The Oviedo Convention: Protecting Human Rights in the biomedical field*

ratified by 29 of the Council's member states, and six more have signed it.<sup>108</sup> The Convention and its Protocols are the only international human rights instruments in the field of biomedicine that are legally binding.<sup>109</sup> The Committee on Bioethics (DH-BIO) is the body responsible for monitoring the scientific development, and leads the work related to possible amendments of the Convention.<sup>110</sup>

In the following three sections, I will elaborate on how the Council of Europe view genetic enhancement and how the organisation justifies this view. In order to do so, I will use three different sources: First, the Oviedo Convention, secondly, a statement from the Committee on Bioethics from 2015 and, finally, a recommendation from the Parliamentary Assembly from 2017.

### 3.2.1 Convention on Human Rights and Biomedicine

The objective of the Oviedo Convention is found in Article 1:

*Parties to this convention shall protect the dignity and identity of all human beings and guarantee to everyone, without discrimination, respect for their integrity and other rights and fundamental freedoms with regard to the application of biology and medicine.*

Interventions on the human genome are mentioned in Article 13, which prohibits hereditary modifications of the human genome, as well as all interventions that are not related to human health:

*An intervention seeking to modify the human genome may only be undertaken for preventive, diagnostic or therapeutic purposes and only if its aim is not to introduce any modification in the genome of any descendants.*

The explanatory report to the Convention elaborates on Article 13, explaining that the article implies that “interventions aimed at modifying genetic characteristics not related to a disease or ailment are prohibited.”<sup>111</sup> Neither the Convention nor the report, explain in depth why such modifications, e.g. genetic enhancement, should be prohibited. However, the report re-

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<sup>108</sup> Council of Europe, Committee on Bioethics, *Chart of signatures and ratifications of*, 14 November 2017 CDBI/INF (2017)

<sup>109</sup> Council of Europe, *The Oviedo Convention: Protecting Human Rights in the biomedical field*,

<sup>110</sup> Convention on Human Rights and Biomedicine (1997), art. 28 and art. 32

<sup>111</sup> Council of Europe, *Explanatory Report to the Convention for the Protection of Human rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human rights and Biomedicine* (1997), para: 90

veals that the article was an answer to a grave concern of the Convention drafters: “[t]he ultimate fear is of intentional modification of the human genome so as to produce individuals or entire groups endowed with particular characteristics and required qualities”<sup>112</sup>.

### 3.2.2 Committee on Bioethics

In the context of new scientific developments, the Committee on Bioethics issued a statement on genome editing technologies in December 2015.<sup>113</sup> Here the Committee underlines that the framework provided by the Oviedo Convention, and in particular Article 13, “remain (...) very relevant today”.<sup>114</sup> The statement furthermore calls for debate “on the fundamental questions raised by these recent technological developments”, using the principles of the Convention as reference for the debate.<sup>115</sup> This implies that the provisions of the Convention “are not the last word on the matter”, according to the 2018 report on Genome Editing and Human Reproduction produced by the Nuffield Council.<sup>116</sup> However, the Committee does not indicate any new stance regarding the prohibition on genetic enhancement, and reiterates the concern from the explanatory report about intentional genetic interventions to produce human beings with particular characteristics.

### 3.2.3 Parliamentary Assembly

On 12 October 2017 the Parliamentary Assembly of the Council of Europe (PACE) adopted a recommendation to the Committee of Ministers on the use of new genetic technologies in human beings, urging all member states “to put in place a national ban on establishing a pregnancy with germ-line cells or human embryos having undergone intentional genome editing”.<sup>117</sup> However, like the 2015 statement from the DH-BIO, the recommendation also calls for public debate on “the medical potential and possible ethical and human rights consequences” regarding the application of genetic technologies.<sup>118</sup> Still, the recommendation emphasises in its first paragraph that using this technology “for enhancement (...) purposes” would be to

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<sup>112</sup> Council of Europe, *Explanatory Report to the Convention for the Protection of Human rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human rights and Biomedicine*, (1997), para: 89

<sup>113</sup> Council of Europe, Committee on bioethics, *Statement on genome editing technologies*

<sup>114</sup> Council of Europe, Committee on bioethics, *Statement on genome editing technologies*

<sup>115</sup> Council of Europe, Committee on bioethics, *Statement on genome editing technologies*

<sup>116</sup> Nuffield Council on Bioethics, *Genome editing and human reproduction: social and ethical issues* (2018), para. 4.44

<sup>117</sup> Council of Europe, *The use of new genetic technologies in human beings*, Recom. 2115 (2017), para. 5.1

<sup>118</sup> Council of Europe, *The use of new genetic technologies in human beings*, Recom. 2115, para. 5.3

abuse these techniques.<sup>119</sup> In the explanatory memorandum to the draft recommendation, rapporteur Petra De Sutter warns that if there is an acceptance of genetic enhancement this “could lead, in turn, to the spectre of eugenics”.<sup>120</sup> She furthermore underlines that another major human rights concern is the effects genome editing might have on future generations: “Changing the genome means changing the common heritage of humanity.”<sup>121</sup> She therefore argues that the precautionary principle must be the guiding principle for all regulation in this area.<sup>122</sup>

### 3.3 Conclusion

The International Bioethics Committee and the Council of Europe both conclude that interventions on the human genome should be admitted for medical reasons only, and never for enhancement purposes. In the various documents I have examined from the Council of Europe, I find that the Council provides very few specific arguments to justify their position. The IBC, on the other hand, provides several arguments in both of their reports.

The arguments I have identified, and which will be assessed in the next chapter are:

- Genetic enhancement may renew eugenics
- Genetic enhancement will both reinforce, and lead to new forms of discrimination and stigmatisation
- Genetic enhancement will infringe on the autonomy of future individuals
- Genetic enhancement will profoundly affect our self-perception as autonomous beings
- Genetic enhancement may jeopardize the equal dignity of human beings

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<sup>119</sup> Council of Europe, *The use of new genetic technologies in human beings*, Recom. 2115 (2017), para. 1

<sup>120</sup> Council of Europe, *The use of new genetic technologies in human beings*, report, Committee on Social Affairs, Health and sustainable development, para. 29

<sup>121</sup> Council of Europe, *The use of new genetic technologies in human beings*, report, Committee on Social Affairs, Health and sustainable development, para. 36

<sup>122</sup> Council of Europe, *The use of new genetic technologies in human beings*, report, Committee on Social Affairs, Health and sustainable development, para. 39

## 4 Assessment of the Arguments

In this chapter will assess the arguments I found in chapter 3 in the light of the bioethical literature. First, in chapter 4.1, I will discuss the concern regarding eugenics, which is brought up by both the IBC and by Council of Europe rapporteur Petra De Sutter. Chapter 4.2 will assess the arguments that enhancement could lead to both reinforced, and new forms of discrimination and stigmatisation. In chapter 4.3 I will discuss both of the IBC's arguments related to the autonomy of future individuals found in their 2003 report. Finally, I will assess the IBC's argument that altering the human genome could jeopardise the equal dignity of human beings.

### 4.1 Eugenics

The first concern I will discuss related to germ-line enhancement is eugenics. This issue is raised both by the IBC and by Council of Europe rapporteur Petra De Sutter.<sup>123</sup> In their 2015 report, the IBC stresses that interventions on the human genome for non-medical purposes will “renew eugenics, disguised as the fulfilment of the wish for a better, *improved* life.”<sup>124</sup> In De Sutter's report, eugenics is discussed in a chapter on potential benefits and risks related to genetic technologies. She explains that:

*[T]here are grave concerns about possible misuse and abuse of the technology with the intention to produce individuals or entire groups endowed with particular characteristics and required qualities. Germline gene therapy could lead to the acceptance of gene therapy for genetic enhancement – which could lead, in turn, to the spectre of eugenics (genetic selection in order to improve genetic traits). I believe history has taught us where this may lead.*<sup>125</sup>

This subchapter will assess the argument that genetic enhancement might renew eugenics. As De Sutter elaborates more on the issue than the IBC, I will primarily assess her argumentation. In order to discuss her argument, I will first attempt to unpack the argument. Secondly, in the following two sections, I will discuss whether all forms of eugenics are wrong and

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<sup>123</sup> Council of Europe, *The use of new genetic technologies in human beings*, report, committee on Social Affairs, Health and sustainable development, para. 29

<sup>124</sup> UNESCO, *Report of the IBC on updating its reflections on the Human Genome and Human Rights* (2015), para. 107

<sup>125</sup> Council of Europe, *The use of new genetic technologies in human beings*, report, committee on Social Affairs, Health and sustainable development, para. 29

whether is it possible to permit some forms of eugenics and still hinder the ‘old eugenics’ from re-emerging.

#### 4.1.1 De Sutter’s Argument

De Sutter is concerned that permitting germ-line interventions could lead to the acceptance of gene therapy for genetic enhancement, which again could lead to “the spectre of eugenics”, i.e. practices aimed at improving the human gene pool. She defines eugenics as “genetic selection in order to improve genetic traits”, which arguably also entail germ-line genetic enhancement.<sup>126</sup> She says she believes “history has taught us where this may lead”,<sup>127</sup> hinting at the controversial history of the first eugenics movements (1870-1950).<sup>128</sup> These movements pursued a negative form of eugenics, i.e. they attempted to reduce the number of undesirable genes, and have come to be associated with compulsory sterilisation programmes, forced euthanasia, racism and the elimination of persons with undesirable genes.<sup>129</sup> For instance, in Sweden, the government identified and sterilised citizens whom they considered to be inferior or deficient,<sup>130</sup> while in Nazi Germany the ‘racial hygiene’ programmes culminated in the Holocaust.<sup>131</sup>

However, as opposed to the negative eugenics practices of the first eugenics movements, improving genetic traits through germ-line enhancement is a *positive* form of eugenics, aiming at improving the human gene pool by increasing the number of desirable genes.<sup>132</sup> Genetic enhancement will alter the genetic make-up of an embryo and enhance its future capacities, but its objective is not, for instance, to improve the human gene pool by eliminating certain persons.

Despite the differences between the ‘old eugenics’ and germ-line enhancement, De Sutter seems nevertheless worried about permitting germ-line genetic technologies. Her argument could possibly be interpreted in two ways: First, that germ-line enhancement is a form of eugenics, and eugenics is always wrong, hence germ-line enhancement is wrong. Secondly,

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<sup>126</sup> Council of Europe, *The use of new genetic technologies in human beings*, report, committee on Social Affairs, Health and sustainable development, para. 29

<sup>127</sup> Council of Europe, *The use of new genetic technologies in human beings*, report, committee on Social Affairs, Health and sustainable development, para. 29

<sup>128</sup> Buchanan et al. *From Chance to Choice*, 30

<sup>129</sup> Nuffield Council on Bioethics, *Genome editing and human reproduction: social and ethical issues* (2018) p.79

<sup>130</sup> Buchanan et al. *From Chance to Choice*, 35

<sup>131</sup> Buchanan et al. *From Chance to Choice*, 37

<sup>132</sup> Resnik, “The Moral Significance of the Therapy-Enhancement Distinction in Human Genetics”, 195

it could be understood as a slippery-slope argument: permitting germ-line enhancement could open the path to unacceptable eugenics practices, such as state-led eugenics programs intended “to produce individuals or entire groups endowed with particular characteristics and required qualities”.<sup>133</sup>

However, proponents of enhancement challenge both of these arguments. They argue that not all forms of eugenics are wrong, and furthermore, that it is possible to permit some forms of eugenics and still hinder the ‘old eugenics’ from re-emerging. The next section will discuss their arguments.

#### 4.1.2 Liberal Eugenics

It is not only De Sutter and the IBC who are worried that permitting genetic enhancement will result in unacceptable eugenics practices. Giubilini et al. explain that, “[a]rguments in favour of human enhancement are often presented by moral conservatives as dangerously close to the ideas that led to Nazi eugenic programmes and other comparable horrors.”<sup>134</sup> However, proponents of enhancement emphasise that there are fundamental differences between the ‘old eugenics’ and the ‘new eugenics’.<sup>135</sup> Below, I will explore one type of new eugenics called ‘liberal eugenics’ and discuss whether liberal eugenics practices can be justified.

Proponents of liberal eugenics argue essentially that individuals have a right to decide whether to use enhancement technologies to enhance themselves or their offspring, and that it is possible to avoid that such practices eventually result in unacceptable “state-led eugenics programmes”.<sup>136</sup> Liberal eugenics prescribes that decisions concerning reproductive selection shall be voluntary (free of coercion), individualistic (“made *by* individual families (...) *for* individual offspring”), and state-neutral (“the government does not promote any particular blueprint for what sorts of people there should be”).<sup>137</sup> Liberal eugenicists tend to justify liberal eugenics in two ways: First, as “an extension of basic reproductive liberty” and secondly, as an analogy with “childrearing practices we commonly accept”, such as the use of special training in order to develop a child’s skills.<sup>138</sup> David Resnik elaborates on the first justifica-

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<sup>133</sup> Council of Europe, *The use of new genetic technologies in human beings*, report, Committee on Social Affairs, Health and sustainable development, para. 29

<sup>134</sup> Giubilini et al. “Challenging Human Enhancement”, 17

<sup>135</sup> Giubilini et al. “Challenging Human Enhancement”, 17

<sup>136</sup> Giubilini et al. “Challenging Human Enhancement”, 17

<sup>137</sup> Fox “The Illiberality of Liberal Eugenics”, 3

<sup>138</sup> Fox “The Illiberality of Liberal Eugenics”, 4

tion, and explains that ‘parental eugenics’, which already “occurs every time people select mates or sperm or egg donors”, can be a morally justified exercise of parental rights.<sup>139</sup> He concludes that, “[t]here is nothing inherently wrong with parental choices to use [germ-line genetic enhancement] to help children achieve health, freedom, and other values”.<sup>140</sup>

However, many commentators object to the idea that decisions regarding genetic interventions fall within the scope of parental rights (as will be further discussed in chapter 4.3). De Sutter also argues against using genetic technology to give individuals particular characteristics, and consequently does not support the idea that anyone, including parents, should have the right to make such decisions.

Another objection to liberal eugenics is that it will not work well in practice, and that it ultimately will lead to a world that is “not all that that different from that championed by eugenicists one hundred years ago”.<sup>141</sup> Robert Sparrow argues for example that the criterion of voluntariness will be very hard to preserve: “Once enhancement becomes possible, refusal to adopt it will appear unreasonable; because the welfare of the child is at stake, parent’s failure to ‘do the right thing’ will appear especially egregious”.<sup>142</sup> Whereas Sparrow focuses on a social pressure to ‘do the right thing’, Michael Sandel is concerned about the role the government might eventually play: the possibility of genetic enhancement combined with the “duty of parents to promote the well-being of their children” will make enhancement “not only permissible, but obligatory.”<sup>143</sup> The state, as *parens patriae*,<sup>144</sup> is also responsible for the welfare of the child, hence, Sandel argues: “Just as the state can require parents to send their children to school, so it can require parents to use genetic technologies (...) to boost their child’s IQ.”<sup>145</sup> Sandel concludes that, “despite the emphasis on individual choice, liberal eugenics implies more state compulsion than first appears”.<sup>146</sup>

However, proponents of liberal eugenics disagree with Sandel and argue that ‘state compulsion’ is never an option in questions concerning the use of genetic enhancement technologies. Although governments can require parents to send their children to school, it does

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<sup>139</sup> Resnik, “The Moral Significance of the Therapy-Enhancement Distinction in Human Genetics”, 195

<sup>140</sup> Resnik, “The Moral Significance of the Therapy-Enhancement Distinction in Human Genetics”, 196

<sup>141</sup> Sparrow “A Not-So-New Eugenics”, 32

<sup>142</sup> Sparrow “A Not-So-New Eugenics”, 40

<sup>143</sup> Sandel, *The Case Against Perfection* p. 78

<sup>144</sup> *Parens patriae*: power of the state to act as the parent of any child in need of protection

<sup>145</sup> Sandel, *The Case Against Perfection* p. 78-79

<sup>146</sup> Sandel, *The Case Against Perfection* p. 78

not follow that they also have to require parents to increase their children's intelligence. It is possible to draw a line between genetic interventions on the one hand and other (non-genetic) measures that governments could demand of parents on the other. This distinction is important for proponents of liberal eugenics, but it is challenged by other proponents of enhancement, such as Dov Fox. The next section will discuss his approach to eugenics.

#### 4.1.3 The Liberality of Liberal Eugenics

In his article "The Illiberality of 'Liberal Eugenics'", Fox argues that proponents of liberal eugenics have misunderstood the central ideas of liberalism.<sup>147</sup> He argues that: "A society guided by liberal philosophy does not leave all childrearing practices to parental discretion."<sup>148</sup> Instead, the liberal commitment to autonomy, which justifies the practice of compulsory education and that parents are required to vaccinate their children, also implies that a liberal state must "mandate genetic interventions that safely enhance comparable natural primary goods in embryos".<sup>149</sup> Examples of 'natural primary goods' are "near-universally beneficial general purpose traits such as memory (...) and general cognitive functioning", Fox explains.<sup>150</sup> However, it is very unclear what he means by 'mandating' genetic interventions, as he later explains that he means for this expression "to be interpreted only in the sense of moral and not legal obligation". One may assume that Fox believes the state should at least strongly encourage certain enhancements, although it is not an option for the liberal state to use coercive measures in such a situation.<sup>151</sup>

As I understand Fox, he argues that for eugenics to be morally acceptable it has to be voluntary and individualistic, but not necessarily state-neutral. One could argue that his emphasis on the role of the state in this context is a step in the direction of the old eugenics where governments initiated eugenics policies and programmes. However, while the old eugenics attempted to eliminate individuals endowed with undesirable genes, germ-line enhancement will only enhance certain traits and not in itself eliminate anyone.

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<sup>147</sup> Fox, "The Illiberality of Liberal Eugenics"

<sup>148</sup> Fox, "The Illiberality of Liberal Eugenics", 7

<sup>149</sup> Fox, "The Illiberality of Liberal Eugenics", 14

<sup>150</sup> Fox, "The Illiberality of Liberal Eugenics", 14

<sup>151</sup> Fox, "The Illiberality of Liberal Eugenics", 15

#### 4.1.4 Conclusion

De Sutter argues that germ-line enhancement might re-new unacceptable eugenics practices. However, not all commentators agree that all forms of eugenics is wrong, or that it will be difficult to prevent the state from interfering in such decisions. Proponents of liberal eugenics are convinced that it is possible to give parents discretion to use enhancement technologies, and still avoid a repetition of the mistakes of the past. On the other hand, Michael Sandel's fear of obligatory enhancements and state compulsion are to some extent confirmed by the position of Dov Fox. He challenges the idea that the new eugenics should uphold the criterion of state-neutrality, and consequently takes the debate one step closer to one of the problematic aspects of the old eugenics.

Nevertheless, although De Sutter's argument succeeds in drawing attention to what the pursuit of desirable genes has lead to previously, it does not quite hit the mark: the eugenics favoured by proponents of enhancement is arguably different from the 'old eugenics', as it does not involve state-led eugenics programmes aimed at eliminating persons with undesirable genes. Consequently, this is not necessarily a very persuasive argument against genetic enhancement.

## 4.2 Discrimination and Stigmatisation

In both of the reports from the International Bioethics Committee I referred to in chapter 3, the Committee stresses that enhancement may result in more stigmatisation and discrimination.<sup>152</sup> In its 2003 report, the Committee states that: "A final objection against (...) enhancement is that even if social agreement on the 'ideal' human being is reached, it will inevitably reinforce stigmatisation and discrimination of those who do not fall into the accepted standards of genetically desirable traits."<sup>153</sup> Furthermore, in their 2015 report, the Committee also warns that enhancement can lead to "new forms of discrimination and stigmatization of those who cannot afford such enhancement or simply do not want to resort to it".<sup>154</sup>

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<sup>152</sup> UNESCO, *Report of the IBC on Pre-implantation Genetic Diagnosis and Germ-line Intervention* (2003), *Report of the IBC on updating its reflection on the human genome and human rights* (2015)

<sup>153</sup> UNESCO, *Report of the IBC on Pre-implantation Genetic Diagnosis and Germ-line Intervention* (2003), para. 99

<sup>154</sup> UNESCO, *Report of the IBC on updating its reflection on the human genome and human rights* (2015) para. 111.

I have not been able to find much literature that deals with this issue directly, but I will use the so-called ‘expressivist objection’ to discuss the message making enhancement technologies available might send, as well as the argument that the use of enhancement might put social virtues such as compassion, care and solidarity under pressure, and therefore lead to a society where discriminatory and stigmatised attitudes thrive.

The structure of this subchapter will be as follows: First, I will elaborate on the meaning of the notions of discrimination and stigmatisation. Secondly, I will draw on the ‘expressivist objection’ in order to discuss how enhancement technologies could be perceived to express a discriminatory attitude towards vulnerable people. Finally, the third part will discuss whether enhancement technologies could put social virtues such as compassion and solidarity under pressure, and consequently lay the foundation for both new forms of discrimination and stigmatisation as well as reinforcing the already existing ones.

#### 4.2.1 Discrimination, Stigmatisation and Human Rights

Article 11 of the *Universal Declaration on Bioethics and Human Rights* (UDBHR) provides that “[n]o individual or group should be discriminated against or stigmatized on any grounds, in violation of human dignity, human rights and fundamental freedoms”.<sup>155</sup> Furthermore, the *Universal Declaration on the Human Genome and Human Rights* (UDHGHR) addresses genetic discrimination specifically: “No one shall be subjected to discrimination based on genetic characteristics that is intended to infringe or has the effect of infringing human rights, fundamental freedoms and human dignity”.<sup>156</sup>

The Explanatory Memorandum to the draft of the UDBHR emphasises that by discrimination the drafters mean “unlawful, unfair or unjustifiable discrimination between people”.<sup>157</sup> Elaborating on the notion of discrimination the Memorandum further explains that, “[d]iscrimination (...) treats a morally neutral and immutable characteristic (such as skin colour, gender, genetic or similar characteristics) as having a negative impact and, based on that illegitimate distinction, similarly situated individuals are treated differently.”<sup>158</sup> Discrimination is not only considered to be morally unacceptable by human rights instruments. Accord-

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<sup>155</sup> *Universal Declaration on Bioethics and Human Rights* (2005) UNESCO, art. 11

<sup>156</sup> *Universal Declaration on the Human Genome and Human Rights* (1997), UNESCO, Art. 6

<sup>157</sup> UNESCO, Explanatory Memorandum on the Elaboration of the Preliminary Draft Declaration on Universal Norms on Bioethics

<sup>158</sup> UNESCO, Explanatory Memorandum on the Elaboration of the Preliminary Draft Declaration on Universal Norms on Bioethics

ing to Andrew Altman, “most philosophical, political, and legal discussions of discrimination proceed on the premise that discrimination is morally wrong and, in a wide range of cases, ought to be prohibited”.<sup>159</sup>

Article 11 of the Universal Declaration on Bioethics and Human Rights also prohibits stigmatisation.<sup>160</sup> Stigmatisation occurs when people are devalued “as a result of a distinguishing characteristic or mark”, H. Rao et al. explains in their article “Stigmatized Attitudes Towards People with Mental Health Problems among Health Professionals”.<sup>161</sup> The Explanatory Memorandum to the draft Declaration explains that stigmatisation may “occur before discrimination is manifested in more direct forms” and that it “often lingers even after the discriminatory laws and policies are abolished”.<sup>162</sup> The Memorandum furthermore explains that “while prohibition of discrimination can be (...) targeted by legal instruments”, the elimination of stigmatisation “requires a longer process of social transformation”.<sup>163</sup>

#### 4.2.2 Social Implications of Genetic Enhancement

The IBC argues in their 2003 report that enhancement may “reinforce stigmatisation and discrimination of those who do not fall into the accepted standards of genetically desirable traits”,<sup>164</sup> i.e., reinforce stigmatisation and discrimination of, for example, people who are disabled or people who belong to a minority group. Furthermore, according to the IBC, enhancement may also create “new forms of discrimination and stigmatization of those who cannot afford such enhancement or simply do not want to resort to it”.<sup>165</sup> This could imply stigmatisation and discrimination in relation to employment, school admission or insurance, for instance.

In the next section I will draw on the ‘expressivist objection’ in order discuss whether making enhancement technologies available could be perceived to express a discriminatory

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<sup>159</sup> Altman, *Discrimination*

<sup>160</sup> *Universal Declaration on Bioethics and Human Rights* (2005) UNESCO

<sup>161</sup> Rao et al. “Stigmatized Attitudes Towards People with Mental Health Problems among Health Professionals”, 280

<sup>162</sup> UNESCO, Explanatory Memorandum on the Elaboration of the Preliminary Draft Declaration on Universal Norms on Bioethics

<sup>163</sup> UNESCO, Explanatory Memorandum on the Elaboration of the Preliminary Draft Declaration on Universal Norms on Bioethics

<sup>164</sup> UNESCO, *Report of the IBC on Pre-implantation Genetic Diagnosis and Germ-line Intervention* (2003), para. 99

<sup>165</sup> UNESCO, *Report of the IBC on updating its reflection on the human genome and human rights* (2015), para. 111.

attitude towards people who are disabled or in other ways vulnerable. After the section on the ‘expressivist objection’ I will discuss whether enhancement could put social virtues such as compassion and solidarity under pressure. These are arguably virtues it is necessary to cultivate in a society in order to counter discrimination and stigmatisation. I will start with the arguments of Dov Fox and Michael Sandel, who both fear that such values can come under pressure, before I discuss Frances Kamm’s counterargument. In section 4.2.2.2.1 I will discuss the measures Fox proposes governments could put in place in order to counteract this development. Finally, I will address Erik Parens’ arguments concerning the ‘goodness of fragility’ and diversity, and how enhancement might affect these.

#### 4.2.2.1 *The ‘Expressivist Objection’*

The so-called ‘expressivist objection’ was first articulated by disability rights activists with regard to prenatal screening<sup>166</sup> and is today used in the debate on selective abortion.<sup>167</sup> The argument claims that making prenatal screening and similar techniques used to “select against the birth of disabled babies” available “express a hostile and discriminatory attitude towards disabled people and send a harmful message about disabled people to them and to wider society”, the Nuffield Council report explains.<sup>168</sup>

The expressivist objection is also relevant with regard to genome editing, the Nuffield Council argues in their report.<sup>169</sup> Accordingly, using genetic technologies to alter the genes of a child who would otherwise have been born with a disability, can in a similar way express a discriminatory attitude towards people who are disabled.<sup>170</sup> There is, however, arguably a difference between altering the genetic make-up of an embryo in order to give birth to a disability-free child, and aborting a foetus that a prenatal genetic test confirmed would be disabled. In the first case, the same child is still born, although disability-free, while in the second case the child is not born.

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<sup>166</sup> Nuffield Council on Bioethics, *Genome editing and human reproduction: social and ethical issues* (2018), p. 83, Box 3.3

<sup>167</sup> Selective abortion: occurs in those cases where a particular foetus is perceived as having undesirable characteristics [http://www.bbc.co.uk/ethics/abortion/medical/selective\\_1.shtml](http://www.bbc.co.uk/ethics/abortion/medical/selective_1.shtml) (BBC)

<sup>168</sup> Nuffield Council on Bioethics, *Genome editing and human reproduction: social and ethical issues* (2018), p. 83, Box 3.3

<sup>169</sup> Nuffield Council on Bioethics, *Genome editing and human reproduction: social and ethical issues* (2018), p. 82, para. 3.60

<sup>170</sup> Nuffield Council on Bioethics, *Genome editing and human reproduction: social and ethical issues* (2018), p.82 para. 3.60

Finally, the question is what harmful message the availability of enhancement technologies could send to people with disabilities and others who already experience stigmatisation and discrimination. Here I will give a couple suggestions. First, the IBC is worried that genetic screening “may foster a culture of ‘perfectionism’ or ‘zero defect’ (...) with the consequence that it could become more and more difficult to accept imperfection and disability as part of *normal* human life”. I believe the same statement can be made with regard to genetic enhancement, thus, permitting enhancement could be perceived as opening the path to a society less tolerant of disability and imperfection. Moreover, permitting enhancement could also send a message about a need to improve human capacities and to produce the “best people”, which could result in a feeling of inadequacy among those who were not born with genetically desirable traits.

The ‘expressivist objection’ draws attention to an important aspect of introducing enhancement technologies, namely the message such technology could send. It is possible that introducing technology that aims to give people the best genes, will send a harmful message to those who are not endowed with ‘desirable’ genes. Hence, the ‘expressivist objection’ gives a valuable perspective in the enhancement debate. Below, I move on to discuss whether enhancement could put social virtues such as compassion and solidarity under pressure.

#### 4.2.2.2 *Compassion, Care and Solidarity*

In his article, *Silver Spoons and Golden Genes: Genetic Engineering and the Egalitarian Ethos*, Dov Fox argues that, “for a social ethos of sharing and solidarity to have moral influence, conditions must exist under which the successful have reason to ascribe the genuine misfortune of others in part to their bad luck”.<sup>171</sup> However, with genetic enhancement, and the control over someone’s genetic make-up that implies, there will be little room left for ‘bad luck’ and, consequently, for compassion, according to Fox:<sup>172</sup>

*[I]t is plausible that the well-off would, in a genetically advanced future, think of disadvantages others as increasingly responsible for the misfortune they suffer, and that this perception, mistaken though it may be, matters in a morally significant way, because it threatens to undermine the incidence and meaning of compassion.*<sup>173</sup>

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<sup>171</sup> Fox, “Silver Spoons and Golden Genes”, 570

<sup>172</sup> Fox, “Silver Spoons and Golden Genes”, 604

<sup>173</sup> Fox, “Silver Spoons and Golden Genes”, 604

Michael Sandel voices the same concern; he argues that access to genetic enhancement would mean an “explosion of responsibility for our own fate, and that of our children”, which “may diminish our sense of solidarity with those less fortunate”.<sup>174</sup>

One possible objection to Sandel’s argument is that it would be unfair to be held responsible for irreversible decisions made by one’s parents concerning one’s genetic make-up. For instance, if one’s parents chose to enhance certain capacities but not others, the potential disadvantages of this decision would not be the fault of the child.

Sandel further argues that if we pursue perfect genetic control we will also lose what he calls our ‘openness to the unbidden’.<sup>175</sup> If parents can choose what kind of children they want, they will no longer have to be taught to be open to the ‘unbidden’, which will be reflected in less open attitudes toward other people, Sandel claims.<sup>176</sup> However, even if we are able to enhance others and ourselves, there are still innumerable other factors that might affect our ‘fate’; there is still “plenty of change and chance for everyone to be subject to”, as Erik Parens writes.<sup>177</sup> Frances Kamm also objects to Sandel’s argument. She argues that so long as we lack complete control, virtues such as understanding and caring about others – and openness to the unbidden – will have to be cultivated.<sup>178</sup> Thus, there will always be a need to be taught to be open to the unbidden, because even if it is possible to predetermine the characteristics of a person, other factors, such as environmental ones, might be just as important.

Although this is true, Fox warns that it is plausible that genetic enhancement will “reinforce the belief in genetic essentialism”, which holds that “genes are the overriding determinant of individual identity”, and thus subdue the fact that we do lack complete control, and consequently curb the effort to cultivate the virtues of openness and understanding.<sup>179</sup>

Nevertheless, although he is concerned about the negative consequences that might be the outcome of widespread genetic enhancement, he does not hold, as mentioned in chapter 2, that genetic enhancement should be prohibited.<sup>180</sup> He therefore discusses which tools that could be employed in order to alleviate these consequences, as further explained in the section below.

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<sup>174</sup> Sandel, *The Case Against Perfection*, p.89

<sup>175</sup> Sandel, *The Case Against Perfection*, p.86

<sup>176</sup> Sandel, *The Case Against Perfection*, p.86

<sup>177</sup> Parens “The Goodness of Fragility”, 143

<sup>178</sup> Kamm, “Is There A Problem With Enhancement?”, 14

<sup>179</sup> Fox, “Silver Spoons and Golden Genes”, 594-95

<sup>180</sup> Fox, “Silver Spoons and Golden Genes”, 620

#### 4.2.2.2.1 *How to Preserve the Virtue of Compassion*

Fox first discusses a suggestion proposed by James Hughes, which is to genetically engineer people to develop the virtue of compassion.<sup>181</sup> Fox does not, however, find Hughes suggestion to be a viable solution to the problem. He argues that enhanced people will not lack “some underlying capacity for the virtue of compassion”, they will rather lack “the right sorts of beliefs (...) which are required in order for that virtue to have the application in practice.”<sup>182</sup> And that is probably beyond what genetic engineering can do.

Fox presents, on the other hand, three regulatory alternatives he believes may be successful. First, he suggests imposing a ‘sin tax’ on those parental interventions that aim to enhance normal offspring characteristics.<sup>183</sup> This tax will send a signal of moral disapproval, Fox argues.<sup>184</sup> Secondly, he proposes to make it less attractive to work as a physician in the field of genetic selection for normal traits by imposing a law that requires these physicians to pay back the public subsidies they received during medical training.<sup>185</sup> Finally, he recommends banning commercial advertising for “designer gametes”.<sup>186</sup> This will “reduce the incidence of offspring enhancement, and (...) render the norms of civic egoism and indifference less likely to seep into the public culture”, he concludes.

However, one could argue that none of these measures will be enough to stop people from enhancing normal offspring characteristics. For how long will a tax be an effective ‘moral’ measure if enhancement is legal? And once employed, physicians will probably not struggle paying back the public subsidies they received. Lastly, with the existence of Internet it is very hard to effectively ban certain advertisements and to control the dissemination of information in general.

In conclusion, it is possible to put in place measures that could counteract negative social implications of enhancement, however, there is no guarantee that such measures will work. Furthermore, with increasing knowledge about genes and how they work, it is not unlikely that the belief in genetic essentialism will make it harder to cultivate values such as

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<sup>181</sup> Fox, “Silver Spoons and Golden Genes”, 614

<sup>182</sup> Fox, “Silver Spoons and Golden Genes”, 614-15

<sup>183</sup> Fox, “Silver Spoons and Golden Genes”, 620

<sup>184</sup> Fox, “Silver Spoons and Golden Genes”, 620

<sup>185</sup> Fox, “Silver Spoons and Golden Genes”, 620

<sup>186</sup> Fox, “Silver Spoons and Golden Genes”, 621

openness and understanding. Hence, the possibility that enhancement could put pressure on a virtues such as compassion and solidarity is an important objection to genetic enhancement.

#### 4.2.2.3 *The Goodness of Fragility*

Erik Parens also finds that genetic enhancement might challenge some of our most fundamental social institutions, and stresses the importance of proceeding with “extreme caution”.<sup>187</sup> His essay *The Goodness of Fragility* suggests that human fragility is valuable, and that we should think carefully about what we might lose if we are in a position to use genetic technology to “reduce our vulnerability to change and chance.”<sup>188</sup> He argues that, “the vulnerability of others not only burdens us (...) but also elicits from us the awesome capacity to care for others.” Still, arguing that there is a need to preserve human fragility and vulnerability might be perceived as a rather insensitive and imprudent view. Should not the objective of society be to put measures in place to reduce people’s vulnerability, e.g. road safety measures in order to reduce people’s vulnerability on the road?

Parens furthermore stresses the need to protect diversity, which he believes could come under pressure from genetic technologies.<sup>189</sup> “Given what appears to be a deep human tendency to fear and hate the different, we ought to be especially vigilant about promoting technologies that could – by engineering sameness – collude with that tendency”.<sup>190</sup> Hence, enhancement technologies might also lead to more discrimination and stigmatisation if they contribute to reducing diversity.

The need to protect diversity is a strong argument against permitting genetic enhancement, provided that the use of enhancement technologies reduces diversity. Hence, is it likely that parents will choose the same types of characteristics for their children? It is perhaps likely that certain enhancements, such as increasing intelligence, will be chosen by all, but parents are also likely to have very different preferences when it comes to selecting characteristics. Additionally, diversity does not only arise from a genetic diversity, environmental factors such as the language one speaks and the experiences one has also make people different from one another.

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<sup>187</sup> Parens “The Goodness of Fragility”, 141

<sup>188</sup> Parens “The Goodness of Fragility”, 141

<sup>189</sup> Parens “The Goodness of Fragility”, 145

<sup>190</sup> Parens “The Goodness of Fragility”, 147

### 4.2.3 Conclusion

In this subchapter I have discussed the IBC's claim that genetic enhancement will lead to reinforced, as well as new forms of stigmatisation and discrimination.

First, I used the 'expressivist objection' to discuss what message introducing enhancement technologies could send. It is possible that introducing technology that aims to give people the best genes, will send a harmful message to those who are not endowed with 'desirable' genes. Hence, the 'expressivist objection' gives a valuable perspective in the enhancement debate.

Secondly, I discussed the argument that enhancement might put social virtues such as compassion, care and solidarity under pressure, which could result in a society where discriminatory and stigmatised attitudes thrive. The main objection to this argument is that it is possible to put in place measures that could counteract such negative consequences. However, there is no guarantee that these measures will work. With increasing knowledge about genetics, it is not unlikely that the belief in genetic essentialism will make it harder to cultivate values such as openness and understanding. Thus, the possibility that enhancement could put pressure on virtues such as compassion and solidarity is an important objection to genetic enhancement.

Finally, I discussed Parens's arguments about the need to protect human fragility and diversity. Human fragility may be valuable, but it is difficult to argue that genetic enhancement should not be permitted in order to preserve human fragility and vulnerability. The need to protect diversity, on the other hand, is a strong argument against enhancement, given that enhancement will result in less diversity.

In conclusion, it is possible that genetic enhancement can result in exacerbated discrimination and stigmatisation, and thus give rise to a very unequal society. Hence, the IBC's arguments discussed in this subchapter convey important objections to permitting genetic enhancement.

### 4.3 Autonomy of Future Persons

The third objection against enhancement I will discuss concerns the autonomy of future persons. The IBC makes two arguments related to the issue of autonomy. Both of these arguments will be discussed in this subchapter. The first argument is:

*[W]e do not have the right to predetermine characteristics of future generations. The notion of justice between generations (...) demands respect for the living conditions of future individuals who should be free to develop their potentialities without being biologically conditioned by the particular conceptions of 'good' and 'bad' human traits that were dominant at the time they were conceived.<sup>191</sup>*

The second argument the IBC makes is that, “genetic enhancement of normal human characteristics (...) would profoundly affect our self-perception as ‘persons’ – that is as autonomous beings. Instead we might consider ourselves to be mere ‘things’ or biological artefacts designed by others.”<sup>192</sup>

I will start by discussing the first argument, which will be done in two parts: First I will address the first claim the IBC makes (“we do not have the right to predetermine characteristics of future generations”), which I will primarily discuss in the context of the right to procreative liberty. Secondly, I will discuss the second part of the statement from the perspective of the interests of future generations. Finally, I will discuss the IBC’s second argument in the light of Habermas’ work.

#### 4.3.1 A Right to Predetermine Characteristics of Future Generations?

The IBC argues that enhancement should not be permitted because no one is given “the right to predetermine characteristics of future generations”.<sup>193</sup> This is the most fundamental argument against germ-line interventions in general, according to the IBC.<sup>194</sup> Proponents of genetic enhancement, on the other hand, naturally disagree with this assertion, and find that there are instances where it is permissible for individuals to make decisions about the characteristics of future generations. They argue, in particular, that parents should be permitted to

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<sup>191</sup> UNESCO, *Report of the IBC on Pre-implantation Genetic Diagnosis and Germ-line Intervention* (2003), para. 97.

<sup>192</sup> UNESCO, *Report of the IBC on Pre-implantation Genetic Diagnosis and Germ-line Intervention* (2003), para. 98.

<sup>193</sup> UNESCO, *Report of the IBC on Pre-implantation Genetic Diagnosis and Germ-line Intervention* (2003), para. 97.

<sup>194</sup> UNESCO, *Report of the IBC on Pre-implantation Genetic Diagnosis and Germ-line Intervention* (2003), para. 97

make choices concerning the genetic make-up of their children, including whether or not to enhance certain characteristics. This parental prerogative is commonly argued based either on the right to parental freedom of procreation or on the right to family autonomy in child rearing and the “parental primary responsibility towards the future child”, according to Maya Sabatello.<sup>195</sup> She explains that the latter justification entails the idea that “parents ought to have the freedom to decide the sort of commitment they want and can undertake”.<sup>196</sup> This could for instance mean the freedom to decide to have a disability-free child if one does not believe one is capable of taking care of a disabled child. However, it could be argued that in terms of enhancement interventions, “the sort of commitment” parents are willing and able to undertake, is less relevant, as this is not a question concerning whether to have a child with a disability or a genetic disease, but about enhancing the child’s characteristics. Therefore, I will turn to the other justification Sabatello mentioned, and discuss whether decisions about prenatal genetic interventions fall within the right to procreative liberty.

#### 4.3.1.1 *The Scope of Procreative Liberty*

John Robertson explains that procreative liberty “is best understood as a liberty or claim-right to decide whether or not to reproduce”.<sup>197</sup> His view is that procreative liberty should extend to choose whether to use genetic knowledge and technologies to have healthy children.<sup>198</sup> Robertson argues that, “reproductive choice in a liberal rights-based society is a basic freedom, including the use of genetic and reproductive technologies that are helpful in having healthy, biologically related offspring”.<sup>199</sup> He emphasises the great value that is placed on procreative liberty,<sup>200</sup> and that it is a natural instinct of parents to desire to have healthy children because “people have strong interests in passing on their genes and in having healthy offspring who will do the same.”<sup>201</sup>

However, Robertson supports the view that some constraints should be placed on procreative liberty.<sup>202</sup> He contends that acceptable use of reproductive technologies requires that they do not “directly harm offspring, families, women, society, and others”, and, furthermore,

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<sup>195</sup> Sabatello, *Children’s Bioethics*, 203

<sup>196</sup> Sabatello, *Children’s Bioethics*, 203

<sup>197</sup> Robertson, “Procreativ Liberty in an Era of Genomics”, 447

<sup>198</sup> Robertson, “Procreativ Liberty in an Era of Genomics”, 484

<sup>199</sup> Robertson, “Procreativ Liberty in an Era of Genomics”, 446

<sup>200</sup> Robertson, “Procreativ Liberty in an Era of Genomics”, 450

<sup>201</sup> Robertson, “Procreativ Liberty in an Era of Genomics”, 444

<sup>202</sup> Robertson, “Procreativ Liberty in an Era of Genomics”, 446

that they serve traditional reproductive goals such as the desire to have genetically related children.<sup>203</sup> In his conclusion, he questions whether this latter criterion is fulfilled in the case of “non-medical enhancement”, as this intervention does not “clearly advance conventionally understood reproductive agendas.”<sup>204</sup>

As opposed to Robertson, proponents of enhancement do not hesitate to argue that it is within the legitimate authority of parents to make decisions concerning ‘non-medical enhancement’ of offspring (hence they either conclude that the traditional reproductive goals criterion can be fulfilled also in these cases, or that the criterion is irrelevant.) James Hughes argues that granting parents the freedom to choose the characteristics of their children would be a “natural extension” of reproductive rights: “If women are allowed the ‘reproductive right’ or ‘choice’ to choose the father of their child, with his attendant characteristics, then they should be allowed the right to choose the characteristics from a catalog.”<sup>205</sup>

Hughes’ conclusion is, however, far from endorsed by bioconservatives. They argue, along the same lines as the IBC, that parents do not possess the right to change their offspring’s genetic make-up, perhaps except in cases where serious genetic diseases can be cured or prevented. Proponents of this view do not accept that procreative liberty naturally extends to decisions concerning prenatal genetic interventions. In the 2002 report *Human Cloning and Human Dignity* the American President’s Bioethics Council, chaired by Leon Kass, asserts that: “[T]he right to decide ‘whether to bear or beget a child’ does not include a right to have a child by *whatever means*. Nor can this right be said to imply a corollary – the right to decide what kind of child one is going to have.”<sup>206</sup>

In a similar vein, it can be argued that there is a significant difference between deciding on whether or not to reproduce and deciding on whether or not to change the genetic characteristics of one’s child. Similarly, there is arguably a difference between choosing the father of one’s child and choosing to use genetic technology to alter or “hand-pick” the traits of one’s child (Hughes’ analogy). In both cases, with the help of genetic technologies, one will reduce chance, and to a larger extent exert direct influence over the outcome, which may also imply a higher degree of responsibility for the result.

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<sup>203</sup> Robertson, “Procreativ Liberty in an Era of Genomics”, 446

<sup>204</sup> Robertson, “Procreativ Liberty in an Era of Genomics”, 484

<sup>205</sup> Hughes, “Embracing Change With All Four Arms”

<sup>206</sup> President’s Council on Bioethics, *Human Cloning and Human Dignity*, 84

However, one possible objection to the bioconservative position in this debate is the fact that parents already are allowed to influence what kind of children they want to have beyond “choosing the father of the child”. Available technologies, such as pre-implantation genetic testing (PGT), give parents an opportunity to make some decisions about the kind of child they want. Hence, such decisions are already, to some degree at least, placed within the authority of parents.

This comparison could be objected to by arguing that there are important differences between PGT and germ-line interventions. The former procedure can be used to select the “best” embryo among several embryos, while the latter procedure involves a selection of characteristics in one embryo. Furthermore, even though PGT is legal and, to some extent at least, a socially acceptable practice, it does not necessarily follow that selecting the characteristics of one’s offspring is a morally acceptable practice.

In conclusion, the moral right to decide whether or not to reproduce does not necessarily extend to determining the characteristics of one’s child.

#### 4.3.2 Interests of Future Generations

In this section I will discuss the second part of the IBC’s argument, which is as follows:

*The notion of justice between generations (...) demands respect for the living conditions of future individuals who should be free to develop their potentialities without being biologically conditioned by the particular conceptions of ‘good’ and ‘bad’ human traits that were dominant at the time they were conceived.*<sup>207</sup>

While the section above discussed the scope of parental freedom of procreation, this section will focus on the interests and rights of the future person. Is genetic enhancement incompatible with respecting the interests of future generations, as the IBC claims? Or is it possible for individuals to be both genetically manipulated and “free to develop their potentialities”? In the first part of this section I will discuss whether genetic enhancement infringes on the freedom and autonomy of future individuals by using the notion of the child’s right to an open future as a starting point. Secondly, I will discuss whether it could be in the interest of future generations to be genetically manipulated.

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<sup>207</sup> UNESCO, *Report of the IBC on Pre-implantation Genetic Diagnosis and Germ-line Intervention* (2003), para. 97.

#### 4.3.2.1 *The Child's Right to an Open Future*

A notion commonly embraced by bioethical commentators in debates on reproductive technologies, is “the child’s right to an open future”.<sup>208</sup> This right implies, Buchanen et al. explain, “that parents have a responsibility to help their children during their growth to adulthood to develop capacities for practical judgement and autonomous choice”.<sup>209</sup> Essentially, the right to an open future means a right to develop these capacities. Joel Feinberg, who articulated this notion in 1980, argues that children have “rights-in-trust” or “anticipatory autonomy rights”, which are rights the child cannot exercise “until later when he is fully formed and capable.”<sup>210</sup> Parents need to respect these rights in order to protect the child’s right to an open future, hence “the existence of [the right to an open future ] (...) sets limits to the ways in which parents can raise their own children”.<sup>211</sup> Feinberg emphasises that the right to an open future is important because it protects the child’s right to self-determination later in life, which is the essential component in giving the child the best chance of self-fulfilment.<sup>212</sup>

Although Feinberg in his 1980 article does not discuss the right to an open future in relation to reproductive genetic technologies, others have later invoked the right in order to challenge the permissibility of cloning and genetic engineering.<sup>213</sup> They argue that using such technology to select the child’s genetic characteristics threatens the future autonomy of the unborn child.<sup>214</sup> This is so, it is argued, because parents then would “point children toward particular life choices”, and, consequently, away from other choices.<sup>215</sup> Michael Sandel objects to this argument because “it wrongly implies that, absent a designing parent, children are free to choose their physical characteristics for themselves”, which is obviously not the case.<sup>216</sup>

However, another way in which genetic enhancement might impair the child’s future autonomy, is in terms of how the enhancement choices of the parents communicate to the

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<sup>208</sup> Buchanan et al., *From Chance to Choice*, 170, Resnik, “The Moral Significance of the Therapy-Enhancement Distinction in Human Genetics”, 195, Nuffield Council Report (2018), 69

<sup>209</sup> Buchanan et al., *From Chance to Choice*, 170

<sup>210</sup> Feinberg, “The Child’s Right to an Open Future”, 112-113

<sup>211</sup> Feinberg, “The Child’s Right to an Open Future”, 117

<sup>212</sup> Feinberg, “The Child’s Right to an Open Future”, 122

<sup>213</sup> Lotz, “Feinberg, Mills, and the Child’s Right to an Open Future”, 537

<sup>214</sup> Lotz, “Feinberg, Mills, and the Child’s Right to an Open Future”, 537

<sup>215</sup> Sandel, *The Case Against Perfection*, 7

<sup>216</sup> Sandel, *The Case Against Perfection*, 7

child what he or she is expected to pursue in life.<sup>217</sup> And as genetic alterations are irreversible choices, the child might experience these expectations to be harder to fight compared to other expectations. For instance it might be harder for a child to quit playing the piano if his parents planned for him to be a world famous pianist and therefore enhanced his musical skills, than if his parents had the same plan but did not alter his genes. In the first case the child might experience that he is “predestined” genetically to have a musical career, and that both his genes and his parents point him in that direction. Whereas in the second case, although his parents encourage him to pursue a musical career, they chose not to intervene in his genes.

Furthermore, expectations arising from the selection of genetic characteristics are created without giving the child a possibility to respond in any way, hence these expectations are “one-sided and unchallengeable”, Jürgen Habermas argues.<sup>218</sup> They are “genetically fixed ‘demands’ [that] cannot be responded to”,<sup>219</sup> as opposed to other expectations that are formed in the process of interaction and communication between parent and child.<sup>220</sup>

Julian Savulescu, on the other hand, does not accept that the selection of genetic traits essentially constitutes a threat to the child’s freedom. He stresses that, “selection and parenting are independent acts”.<sup>221</sup> Thus, if parents have unbearable expectations toward their child that limit the child’s freedom, the problem lies not in the act of selection, but in their parenting. Moreover, Savulescu does not only find that selecting one’s offspring’s characteristics does not infringe on the child’s freedom, he also finds that enhancement technologies can contribute to *increase* freedom: “Engineering perfect pitch or increasing intelligence or giving a child a talent *increases* options and freedom”.<sup>222</sup>

Hence, it is hard to argue that genetic interventions are inherently incompatible with the child’s right to an open future, as the right mainly should ensure that parents do not close off “opportunities that would otherwise be available to their children”.<sup>223</sup> Instead genetic enhancements could have the effect of *increasing* the child’s opportunities, therefore “recognizing the right to an open future is compatible with according substantial discretion to parents to

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<sup>217</sup> Savulescu, “Bioethics: Why Philosophy is Essential for Progress”, 28

<sup>218</sup> Habermas, *The Future of Human Nature*, 51

<sup>219</sup> Habermas, *The Future of Human Nature*, 51

<sup>220</sup> Habermas, *The Future of Human Nature*, 61

<sup>221</sup> Savulescu, “Bioethics: Why Philosophy is Essential for Progress”, 29

<sup>222</sup> Savulescu, “Bioethics: Why Philosophy is Essential for Progress”, 28

<sup>223</sup> Buchanan et al., *From Chance to Choice*, 170

use genetic interventions (...) to attempt to give their children what they might consider to be the best life possible”, Allen Buchanan et al. concludes.<sup>224</sup>

In conclusion, it is difficult to argue that all forms of genetic enhancement are incompatible with respecting the autonomy of future persons. Consequently, this part of the IBC’s argument is not very convincing.

#### 4.3.2.2 *The Benefits of Genetic Manipulation*

In the light of the conclusions of Savulescu and Buchanan et al., one must ask whether the focus should rather be on the benefits of enhancement and how it can further the interests of future generations. “There are enhancements of capacities and abilities that are as plausibly a benefit from nearly any evaluative perspective as the comparable loss of the capacity and ability would be a harm”, Buchanan et al. argues.<sup>225</sup> What he has in mind is the enhancement of what he calls “general-purpose means”.<sup>226</sup> These are means that are “useful and valuable in carrying out nearly any plan of life”,<sup>227</sup> hence, enhancing general-purpose means would not infringe on the right to an open future, and future generations would neither be “biologically conditioned by the particular conceptions of ‘good’ and ‘bad’ human traits that were dominant at the time they were conceived”.<sup>228</sup>

In his article “Procreative Beneficence: Why We Should Select the Best Children”, Savulescu argues that parents have a moral obligation “to have the best children”.<sup>229</sup> He writes in response to the introduction of pre-implantation genetic diagnosis, but his arguments are also relevant in the context of germ-line enhancement. Savulescu argues that, “parents should select the child (...) who is expected to have the best life, or at least as good a life as the others, based on the relevant available information”.<sup>230</sup> Hence, if enhancement techniques were made available, parents would have a moral obligation to use these techniques in order to give their child the best genes, and consequently the best life.

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<sup>224</sup> Buchanan et al., *From Chance to Choice*, 170

<sup>225</sup> Buchanan et al., *From Chance to Choice*, 168

<sup>226</sup> Buchanan et al., *From Chance to Choice*, 167

<sup>227</sup> Buchanan et al., *From Chance to Choice*, 167

<sup>228</sup> UNESCO, *Report of the IBC on Pre-implantation Genetic Diagnosis and Germ-line Intervention* (2003), para. 97.

<sup>229</sup> Savulescu, “Procreative Beneficence”, 415

<sup>230</sup> Savulescu, “Procreative Beneficence”, 415

### 4.3.3 Our Self-Perception as Autonomous Beings

In this section I move on to discuss the second argument the IBC made, claiming that genetic enhancement would “profoundly affect our self-perception as ‘persons’ – that is as autonomous beings.”<sup>231</sup> Their concern is that we “might consider ourselves to be mere ‘things’ or biological artefacts designed by others.”<sup>232</sup> Hence, their argument is not whether those who have been ‘designed’ by their parents are in fact less autonomous than those children who have not been ‘designed’, but rather that genetically enhanced people would perceive themselves in a different way compared to non-enhanced people. This issue is not, to my knowledge, discussed by many authors in the bioethical literature. However, one of the few who do discuss it, is the German philosopher Jürgen Habermas. Although Habermas in his book *The Future of Human Nature* is primarily concerned with the effects of preimplantation genetic diagnosis and embryo selection, his reflections are also relevant for germ-line genetic enhancements.<sup>233</sup>

Habermas argues, in line with the IBC, that enhancement technologies could potentially change how human beings, whose characteristics have been predetermined, perceive themselves.<sup>234</sup> He is especially concerned that it might affect their awareness of freedom.<sup>235</sup> Habermas explains that, “[w]e experience our own freedom with reference to something, which by its very nature, is not at our disposal”.<sup>236</sup> This reference point, Habermas argues, is the moment of birth, which demarcates what Habermas calls the ‘natural fate’ from the ‘socialisation fate’ of a person.<sup>237</sup> He further explains:

*It is only by referring to this difference between nature and culture, between beginnings at our disposal, and the plasticity of historical practices that the acting subject may proceed to the self-ascriptions without which he could not perceive himself as the initiator of his actions and aspirations.*<sup>238</sup>

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<sup>231</sup> UNESCO, *Report of the IBC on Pre-implantation Genetic Diagnosis and Germ-line Intervention* (2003), para. 98

<sup>232</sup> UNESCO, *Report of the IBC on Pre-implantation Genetic Diagnosis and Germ-line Intervention* (2003), para. 98

<sup>233</sup> Nuffield Council on Bioethics, *Genome Editing and Human Reproduction: Social and Ethical Issues* (2018), p.68

<sup>234</sup> Habermas, *The Future of Human Nature*, 58-60

<sup>235</sup> Habermas, *The Future of Human Nature*, 58-60

<sup>236</sup> Habermas, *The Future of Human Nature*, 58

<sup>237</sup> Habermas, *The Future of Human Nature*, 58-59

<sup>238</sup> Habermas, *The Future of Human Nature*, 59

Habermas continues: “The fact that this natural fate, the past before our past, (...) is not at our human disposal seems to be essential for our awareness of freedom.”<sup>239</sup> Hence, by using enhancement technologies humans would influence or “socialise” this ‘natural fate’, and thus jeopardise the ‘designed’ person’s understanding of himself as an autonomous being. Habermas concludes that, “[a] person (...) who would be the sole product of a suffered socialization fate would see his ‘self’ slip away”.<sup>240</sup>

However, there are possible objections to Habermas’ argumentation. Whether a “socialisation” of their natural fate will change how enhanced persons view themselves, is arguably questionable. Factors other than genetic can also influence humans’ self-perception. For instance, if a couple predetermined the characteristics of their child, but emphasised both vocally and in practice, during the child’s upbringing, that the child was an autonomous being with a free will, a person and not an object, this child might perceive itself as more autonomous and free compared to a child raised by parents who did not select or enhance any characteristics, but left their child with very little room to express her own opinions and make her own decisions. Thus, even if enhancement interventions would affect the self-perception of ‘designed’ persons, other factors could plausibly counterbalance such effects. Consequently, this is not a very persuasive argument against genetic enhancement.

#### 4.3.4 Conclusion

In this subchapter I have explored two arguments against genetic enhancement related to the autonomy of future persons.

The first argument consisted of two interrelated claims against genetic enhancement: first, that no one is entitled to predetermine the characteristics of future generations, and, secondly, that in order to respect the interests of future generations prenatal genetic interventions should not be permitted. Both of these arguments are challenged in the bioethical literature.

First, it is argued that procreative liberty naturally extends to decisions concerning one’s offspring’s genetic make-up. However, others argue that it does not necessarily follow that the moral right to decide whether or not to reproduce also extends to determining the characteristics of one’s child. Furthermore, even though the scope of procreative liberty has evolved to give parents an opportunity to make some decisions about what kind of child they want (such as through PGT), it does not necessarily follow that selecting the characteristics of

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<sup>239</sup> Habermas, *The Future of Human Nature*, 60

<sup>240</sup> Habermas, *The Future of Human Nature*, 60

one's offspring is a morally acceptable practice. In conclusion, the moral right to decide whether or not to reproduce does not necessarily extend to determining the characteristics of one's child.

Regarding the second part of the IBC's first argument, it is hard to endorse the conclusion that all forms of genetic enhancement are incompatible with respecting that individuals "should be free to develop their potentialities".<sup>241</sup> Enhancements could, on the other hand, be highly beneficial without infringing on the freedom of future generations, at least if assessed from the perspective of the child's right to an open future. Consequently, this is not a very convincing argument against genetic enhancement.

The second argument the IBC made is endorsed by Habermas, who also warns that enhancement technologies could affect individuals' self-perception as autonomous beings. The argument should be included in the debate on how enhancement interventions may affect the self-identity of 'designed' persons. However, as I have pointed out, non-genetic factors could plausibly counterbalance negative effects related to self-perception, thus, this is not a very persuasive argument against genetic enhancement.

#### **4.4 The Human Genome and Human Dignity**

The last argument I will discuss concerns the relation between the human genome and human dignity. In their 2015 report the IBC elaborates on the concept of dignity in relation to Article 1 of the *Universal Declaration on the Human Genome and Human Rights* (UDHGHR), which states that: "The human genome underlies the fundamental unity of all members of the human family as well as the recognition of their inherent dignity and diversity. In a symbolic sense it is the heritage of humanity".<sup>242</sup> The Committee continues:

*Nature is often understood as a limit to human freedom. At least in this case, building exactly on Article 1 of the UDHGHR, the argument is made that it should be rather considered as its premise, so that interventions on the human genome should be admitted only for preventive, diagnostic or therapeutic reasons and without enacting modifications for descendants, as affirmed in Article 13 of the Oviedo Convention. The al-*

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<sup>241</sup> UNESCO, *Report of the IBC on Pre-implantation Genetic Diagnosis and Germ-line Intervention* (2003), para. 97.

<sup>242</sup> *Universal Declaration on the Human Genome and Human Rights*, UNESCO (1997)

*ternative would be to jeopardize the inherent and therefore equal dignity of all human beings.*<sup>243</sup>

In order to assess the argument, I will first briefly elaborate on Article 1 of the UDHGHR, in order to clarify the contents of this article. Secondly, I will try to unpack the IBC's argument, and finally, I will discuss whether changing the human genome could jeopardise the equal dignity of human beings. As this issue, to my knowledge, is not very often discussed in the bioethical literature, this subchapter will draw less on bioethical works than the previous subchapters have.

#### 4.4.1 Article 1 of the UDHGHR

The Universal Declaration on the Human Genome and Human Rights was, as mentioned in the previous chapter, the very first bioethics declaration UNESCO adopted.<sup>244</sup> As indicated in its title, the Declaration underlines the importance of the human genome in relation to human rights. Article 1 of the Declaration explains that the human genome “underlies the fundamental unity of all members of the human family, as well as the recognition of their inherent dignity and diversity.”<sup>245</sup> It furthermore states that the human genome “[i]n a symbolic sense (...) is the heritage of humanity”.<sup>246</sup> Thus, in the Declaration the human genome plays a fundamental role “underpinning both the class unity of all human beings and also the recognition of their inherent dignity and diversity”, the Nuffield Council comments in their 2018 report.<sup>247</sup> Deryck Belyveld et al. explains that the Article also is in accordance with Article 1 of UNESCO's Declaration on Race and Racial Prejudice which states that: “All human beings belong to a single species (...) [t]hey are born equal in dignity and rights and all form an integral part of humanity.”<sup>248, 249</sup>

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<sup>243</sup> UNESCO, *Report of the IBC on updating its reflections on the Human Genome and Human Rights* (2015), para. 107

<sup>244</sup> UNESCO, *Report of the IBC on updating its reflections on the Human Genome and Human Rights* (2015), para. 2

<sup>245</sup> *Universal Declaration on the Human Genome and Human Rights*, UNESCO (1997)

<sup>246</sup> *Universal Declaration on the Human Genome and Human Rights*, UNESCO (1997)

<sup>247</sup> Nuffield Council on Bioethics, *Genome editing and human reproduction: social and ethical issues* (2018), p.115, para. 4.39

<sup>248</sup> *Declaration on Race and Racial Prejudice*, UNESCO (1978)

<sup>249</sup> Belyveld et al., *Human Dignity in Bioethics and Biolaw*, 38

#### 4.4.2 The Argument of the IBC

The argument articulated in the 2015 IBC report uses Article 1 of the UDHR to argue that interventions on the human genome for non-medical reasons, as well as heritable modifications of the human genome, should not be admitted. The IBC explains that, “nature is often understood as a limit to human freedom”, however, in relation to Article 1 “it should rather be considered as its premise”.<sup>250</sup> In the last section of the report, the IBC emphasises that the human genome should be considered as “one of the premises of freedom itself and not simply as raw material to manipulate at leisure.”<sup>251</sup> Thus, the IBC seems to argue that there is a link between the human genome and human freedom, i.e. that there is something in the human genome that “ensures” that human beings are free, perhaps in contrast to the genome of other species. Consequently, there is a need to protect the human genome from interventions that could jeopardise the human genome as a source of freedom. The IBC’s conclusion is therefore that only preventive, diagnostic or therapeutic interventions on the human genome should be admitted.

The IBC is furthermore worried that non-medical and hereditary modifications could “jeopardize the inherent and therefore equal dignity of all human beings”.<sup>252</sup> Hence, the human genome is not only a premise of freedom; the IBC also seems to argue that it is a premise of equal dignity. In the following section I will pursue this latter discussion, as it is rather unclear what the IBC means by the human genome being a premise of freedom, and therefore difficult to discuss this issue any further.

#### 4.4.3 Equal Dignity and the Human Genome

Scholars have proposed a number of different definitions of the concept of dignity, however here I find it most relevant to focus at the concept from a human rights perspective. Article 1 of the Universal Declaration of Human Rights asserts that: “All human beings are born free and equal in dignity and rights.”<sup>253</sup> Accordingly, *every human being* has dignity, and all human beings are born with the *same dignity* and the same human rights. The notion of “inherent dignity” found in Article 1 of the UDHR, as well as in many other international human

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<sup>250</sup> UNESCO, *Report of the IBC on updating its reflections on the Human Genome and Human Rights* (2015), para. 107

<sup>251</sup> UNESCO *Report of the IBC on updating its reflections on the Human Genome and Human Rights* (2015), para. 128

<sup>252</sup> UNESCO *Report of the IBC on updating its reflections on the Human Genome and Human Rights* (2015), para. 107

<sup>253</sup> *Universal Declaration of Human Rights* (1948)

rights instruments, emphasises that human dignity is intrinsic and can never be taken away.<sup>254</sup> Several of the instruments explicitly link human dignity to human rights by stating that these rights “derive from the inherent dignity of the human person”,<sup>255</sup> affirming that human dignity is a source and foundation for human rights law.

Article 1 of the UDHR furthermore states that: “The human genome underlies (...) the recognition of [all members of the human family’s] inherent dignity and diversity.”<sup>256</sup> Thus, the Declaration communicates that there is a strong link between the human genome and human dignity. The human genome demonstrates that “all humans belong to the same family” and therefore, naturally, have equal dignity.<sup>257</sup> The argument made in the IBC report is essentially that interventions on the human genome that are not in accordance with Article 13 of the Oviedo Convention might threaten this natural equality in dignity and should therefore be prohibited in order to protect the human genome and, consequently, protect human dignity and human rights.

However, one major objection to this argument concerns the notion of the human genome. The drafters of the Declaration decided against including a definition of the notion, since there was a “risk of scientific definitions becoming obsolete due to the rapidity with which new discoveries were made.”<sup>258</sup> Although no specific definition is provided in the Declaration, commentators still find the notion to be “biologically incoherent”, because there is no “stable pool of genetic variations that can be characterised as ‘the human genome’”.<sup>259</sup> Such an idea is “a fiction” and would hinder all further evolution, according to the Nuffield Council.<sup>260</sup> Hence, it is difficult to link human dignity to “the possession of a particular kind of genome (...) since the human genome is not a single, stable thing”.<sup>261</sup>

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<sup>254</sup> Schachter, “Human Dignity as a Normative Concept”, 849

<sup>255</sup> Such as: the International Covenant on Civil and Political Rights (1966), the International Covenant on Economic, Social and Cultural Rights (1966) and the Convention Against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (1984)

<sup>256</sup> *Universal Declaration on the Human Genome and Human Rights*, UNESCO (1997)

<sup>257</sup> Beyleveld et al., *Human Dignity in Bioethics and Biolaw*, 38

<sup>258</sup> UNESCO, *Birth of the Universal Declaration on the Human Genome and Human Rights* (1999), 58

<sup>259</sup> Nuffield Council on Bioethics, *Genome Editing and Human Reproduction: Social and Ethical Issues* (2018), p.115, para. 4.39

<sup>260</sup> Nuffield Council on Bioethics, *Genome Editing and Human Reproduction: Social and Ethical Issues* (2018), p.115, para. 4.39

<sup>261</sup> Nuffield Council on Bioethics, *Genome Editing and Human Reproduction: Social and Ethical Issues* (2018), p. 92, para. 3.82

Consequently, building on the fact that ‘human genome’ is not stable, but something that evolves, it can be argued that one would need to alter the genome in a fundamental way in order to jeopardise the idea of the inherent and equal dignity of all human beings. It is hard to categorise germ-line interventions which remove a genetic disease, or enhancements which do not, using one of Frances Kamm’s expressions, “introduce improvements that no human being has yet evidenced”<sup>262</sup> as such fundamental changes, and these kinds of interventions are, for instance, arguably the most relevant for parents to choose for their offspring. However, it is possible to imagine that genome editing in the future could result in a schism between so-called ‘gene-rich’ and ‘gene-poor’ people leading to a distinction between those who are “merely human” and those who are “something beyond human”, or it could even result in a new species.<sup>263</sup> This possibility will be discussed briefly below.

#### 4.4.4 A Posthuman Future?

A few bioethical commentators have voiced that they fear a future scenario where a new species of humans have been developed as a result of genome editing.<sup>264</sup> George J. Annas et al. argue for instance that inheritable genetic alterations “are techniques that can alter the essence of humanity itself (and thus threaten to change the foundation of human rights) by taking evolution into our own hands and directing it toward the development of a new species, sometimes termed ‘posthuman’.”<sup>265</sup> In this context, where a long-term perspective is implied, the IBC’s argument perhaps makes more sense; it is not obvious that all humans are born equal in dignity and rights if we do not belong to the same species anymore.

However, the likelihood of this scenario materialising is questionable. Even if individual human beings could be genetically engineered, it would be hard to create a new ‘human nature’ or a new species, as the human gene pool is very large. In a similar vein, Frances Fukuyama explains that, “any future attempt to eugenically improve the human race would be quickly overwhelmed by natural population growth”.<sup>266</sup> Still, Fukuyama acknowledges that one should be careful in one’s predictions about the future, as the speed of technological de-

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<sup>262</sup> Kamm, “Is There a Problem With Enhancement?” , 5. She does not discuss human dignity in her article, but uses this expression in order to distinguish between different types of enhancements

<sup>263</sup> Nuffield Council on Bioethics, *Genome Editing and Human Reproduction: Social and Ethical Issues* (2018), p. 93, para. 3.85

<sup>264</sup> Nuffield Council on Bioethics, *Genome Editing and Human Reproduction: Social and Ethical Issues* (2018), p. 93-95

<sup>265</sup> Annas et al., “Protecting the Endangered Human”, 153

<sup>266</sup> Fukuyama, *Our Posthuman Future*, 79

velopments can be remarkable.<sup>267</sup> If a group of scientists decided to use CRISPR/cas9 to attempt to create a new species of humans, it is a possibility that they would succeed, which could challenge the idea of equal dignity of all humans.

#### 4.4.5 Conclusion

This subchapter has discussed whether non-medical modifications of the human genome could “jeopardize the inherent and therefore equal dignity of all human beings”.<sup>268</sup> The argument links human dignity to the possession of a particular genome, which is unwise, because there is no single, stable human genome; the notion of a common human genome is ‘biologically incoherent’. Hence, it is hard to argue that altering the genome for non-medical reasons would jeopardise the idea that human beings are born equal in dignity, at least so long as interventions on the genome do not lead to the creation of a new human species. Consequently, the argument is not a very convincing objection to genetic enhancements parents would typically choose for their offspring.

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<sup>267</sup> Fukuyama, *Our Posthuman Future*, 79

<sup>268</sup> UNESCO *Report of the IBC on updating its reflections on the Human Genome and Human Rights* (2015), para. 107

## **5 Conclusion**

This thesis has attempted to assess the strengths and weaknesses of the arguments against genetic enhancement articulated by the International Bioethics Committee and the Council of Europe in the light of the bioethical literature. The aim of the thesis has been to contribute to the discussion on the ethics of enhancement, as technological advances are about to render germ-line interventions possible. It is critical at this point to discuss the consequences of introducing new genetic technologies, and the framework of universal human rights is the natural foundation for such a discussion. In this final chapter, I will first summarize my findings and draw a conclusion. Lastly, I will suggest a path for future inquiries in the field of bioethics and human rights.

### **5.1 Summary of findings**

The International Bioethics Committee and the Council of Europe both conclude that interventions on the human genome should be admitted for medical reasons only, and never for enhancement purposes. In the various documents I examined from the Council of Europe, I found that the Council provides very few specific arguments to justify their position. The IBC, on the other hand, provides several arguments in both of their reports (this is done most systematically in the 2003 report). I have explored all the specific arguments against enhancement I found in the light of the bioethical literature. In the sections below I will summarize my findings.

#### **5.1.1 Eugenics**

The first argument I discussed was related to the fear of eugenics. This is a concern mentioned by many authors in the bioethical literature. Some bioconservatives and moderates endorse it, while proponents of enhancement dismiss this argument, explaining that the ‘old eugenics’ and the ‘new eugenics’ are two very different things.

The argument’s most valuable contribution is perhaps that it draws attention to what the pursuit of desirable genes has lead to previously, urging us to proceed with caution. However, the main problem with the argument is that it does not quite hit the mark: the ‘liberal eugenics’ that proponents of enhancement propose does not imply a realisation of what eugenics is mostly associated with; state-led eugenics programmes aimed at eliminating persons with undesirable genes. Consequently, this is not necessarily a very persuasive argument against genetic enhancement.

### 5.1.2 Discrimination and Stigmatisation

The second argument I assessed was the IBC's concern that enhancement would lead to an exacerbation of discrimination and stigmatisation. I was not able to find much literature that dealt with this issue directly, but I used the 'expressivist objection' to discuss the message making enhancement technologies available might send, as well as the argument that the use of enhancement might put social virtues such as compassion, care and solidarity under pressure, and therefore lead to a society where discriminatory and stigmatised attitudes thrive.

All bioethical commentators acknowledge that enhancement might have adverse social implications, however proponents of enhancement argue that it is possible to counteract the negative outcomes to such an extent that enhancement should still be permitted. The possibility of measures that could counteract reinforced and new forms of discrimination and stigmatisation is perhaps the most important objection to the IBC's argument. Nevertheless, there is no guarantee that such measures will work. Consequently, this is a strong argument against genetic enhancement, especially considering the plausibility that genetic enhancement might, as Fox notes, "reinforce the belief in genetic essentialism".<sup>269, 270</sup> This could make it even harder to fight discrimination and stigmatisation related to genetic traits.

### 5.1.3 Autonomy of Future Persons

The third subchapter in chapter 4 discussed two arguments related to the autonomy of future individuals. The first argument concerned the right to predetermine characteristics of future generations and whether future individuals are "free to develop their potentialities" if their characteristics have been predetermined. The scope of procreative liberty and the autonomy of future individuals are central issues in the bioethical literature. With the introduction of new reproductive technologies, the scope of procreative liberty has grown to include new legal rights in many countries. However, it does not necessarily follow that the moral right to decide whether or not to reproduce also extends to determining the characteristics of one's offspring. Hence, this is an important objection to the permissibility of "parental eugenics".

Regarding the second part of the argument concerning the autonomy of future individuals, it is difficult to argue that all forms of genetic enhancement are incompatible with respecting the autonomy of the future person. It is, for instance, possible to enhance general purpose

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<sup>269</sup> Genetic essentialism: "Genes are the overriding determinant of individual identity" Fox, "Silver Spoons and Golden Genes", 594

<sup>270</sup> Fox, "Silver Spoons and Golden Genes", 594-95

means and still respect the child's right to an open future. Consequently, this argument is not very convincing.

In the second part of subchapter 4.3, I discussed the concern that genetic enhancement would affect how individuals perceive themselves as autonomous beings. I was only able to find one author, in addition to the Nuffield Council, who discusses this issue, the German philosopher Jürgen Habermas. He argues, in line with the IBC, that the use of enhancement technologies could potentially change whether human beings, whose characteristics have been predetermined, see themselves as autonomous persons. The argument should be included in the debate on how enhancement interventions may affect the self-identity of 'designed' persons. However, a difficulty with the argument is that it puts too much emphasis on genetic factors, and overlooks the role non-genetic factors can play in the formation of identity. Hence, this is not necessarily a very persuasive argument against genetic enhancement.

#### 5.1.4 The Human Genome and Human Dignity

The last argument I assessed concerned the fear that altering the human genome for non-medical purposes could "jeopardize the inherent and therefore equal dignity of all human beings".<sup>271</sup> I was not able to find much literature that dealt with this issue directly.

The main problem with the argument is that the notion of a stable, common human genome is biologically incoherent. Hence, it is hard to argue that altering the genome would jeopardise the idea that human beings are born equal in dignity and rights, at least so long as interventions on the genome do not lead to the creation of a new human species. Consequently, this argument is not a very convincing objection to genetic enhancements parents would typically choose for their offspring.

In conclusion, not all the arguments articulated by the IBC and the Council of Europe are convincing. However, it is not the number of convincing arguments that counts, but the contents of these arguments. The argument concerning discrimination and stigmatisation emphasise the sort of society genetic enhancement can give rise to, and although it is hard to predict the exact consequences of permitting enhancement, one need to ask whether it is worth taking the risk. The IBC and the Council of Europe conclude that it is not a risk worth taking; in or-

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<sup>271</sup> UNESCO, *Report of the IBC on updating its reflection on the human genome and human rights* (2015) para. 107.

der to protect the dignity and rights of vulnerable persons and future generations there should always be a ban on genetic enhancement.

## **5.2 Future Inquiries**

This thesis has assessed the arguments against genetic enhancement formulated by the IBC and the Council of Europe in the light of the bioethical literature. It would be interesting to assess each of these arguments more in-depth than what has been possible to do here. Furthermore, as the thesis has shown that many commentators in the bioethical literature are in favour of permitting enhancement when the procedure is acceptably safe, contrary to the recommendations of the two human rights organisation, it would also be interesting to explore more in-depth the underlying causes for the different conclusions that are reached regarding the ethics of enhancement.

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